

## Young-onset dementia

May 2018

### Key findings

**Dementia is commonly considered to be something that only affects older people – but this is not the case.**

**Younger people living with dementia may face very different challenges to older people – including staying in employment, paying a mortgage, or caring for young children.**

**But there is very little awareness of how dementia affects younger people, and very little support to help people continue to live their lives after diagnosis.**

**The Mayor's plans for a dementia-friendly city must be reflective of the varied nature of dementia and how it affects people of all ages.**

**Specific action is needed on transport, employment and supporting social inclusion, as well as addressing a lack of specialised health and care support.**

**The voices and experiences of younger people living with dementia are crucial to making London dementia-friendly. The Mayor should ensure that there are effective plans in place to enable people living with young-onset dementia to contribute to his plans and policies.**



**The London Assembly Health Committee** held an investigation into young-onset dementia in London. In our formal committee session, we spoke to experts from the Dementia Research Centre at UCL, the Alzheimer's Society, the Dementia Clinical Network NHS England (London region) and Transport for London. We also heard directly from Londoners living with young-onset dementia about their experiences. Outside of the committee session we received further evidence from people living with young-onset dementia and the organisations that support them. This report sets out our key findings and makes recommendations to the Mayor on how to ensure his plans for a dementia-friendly London are inclusive of younger people living with the condition.

## Young-onset dementia

May 2018

### What is young-onset dementia?

Dementia refers to a group of degenerative brain disorders that lead to progressive decline in cognitive function. The term 'dementia' is used to describe a collection of symptoms, which can include decline in reasoning and communication skills, changes to personality, and a gradual loss of skills needed to carry out daily activities, as well as the memory loss that most people traditionally associate with dementia. These symptoms are caused by structural and chemical changes in the brain. This can be the result of physical diseases such as Alzheimer's disease, but there are many other conditions that can also lead to dementia.

Dementia is often thought of as an issue that only affects older people. However, it can affect people at much younger ages. People who develop dementia before the age of 65 are referred to as having **young-onset dementia (YOD)**.<sup>1</sup> Depending on the underlying causes of their dementia, they may experience similar symptoms to older people or they may have very different symptoms. Younger people are more likely to have rarer forms of dementia, and the progression of the condition can also be different than for older people. This can make it difficult to recognise dementia in younger people and respond appropriately to their needs.

### How many people in London are living with young-onset dementia?

It is difficult to know exactly how many people in London are living with young-onset dementia. NHS England (London region) estimates that at least 2,300 people are living with young-onset dementia.<sup>2</sup> However, other organisations suggest that the actual figure may be much higher. Around 80,000 Londoners of all ages live with dementia: Young Dementia UK suggests that between five and nine per cent of all cases of dementia may be young-onset.<sup>3</sup> For London this would equate to between 4,000 and 7,200 people. The lack of solid data around how many people are living with young-onset dementia makes it difficult to plan effective services.

People with a learning disability are at greater risk of developing dementia at a younger age. Studies have shown that one in ten people with a learning disability develop young-onset dementia between the ages of 50-65. The number of people with Down's syndrome who develop dementia is even higher, with one in 50 developing the condition aged 30-39, one in ten aged 40-49, and one in three in their 50s.<sup>4</sup>

## Young-onset dementia

May 2018

### Younger people living with dementia face specific challenges...

Typically, people who are diagnosed with young-onset dementia are in very different circumstances in life from older people with dementia. They are more likely to be in paid employment, have young or teenage children living at home, be otherwise fit and healthy, and have significant financial and other commitments, such as caring for an older parent. All these factors influence the experience of living with dementia and influence the support that people need to maintain a good quality of life.

A diagnosis of young-onset dementia also has a wider impact on family networks, and family members who become carers. This is often spouses, and may also include elderly parents or children and teenagers who are drawn unexpectedly into caring roles and may consequently need to make significant lifestyle changes. Specific information and support is needed to carry on working, or retire early, manage finances before a pension can be drawn, or navigate services such as arranging childcare or getting legal advice. But we heard that access to this support is highly variable across London. This means that people living with young-onset dementia can end up in debt, at threat of losing their home, socially isolated and at greater risk of depression and anxiety.

We heard that being able to access the right information at the right time was vital in supporting people with dementia to live well. However, there were concerns that people are bombarded with information at the point

of diagnosis and then left with little help about ongoing management of key aspects of their life.

“Often, people have difficulty accessing legal advice. Solicitors are not necessarily affordable for everyone and there is an issue of accessibility and equality in terms of how people get legal advice”

**The Dementia Law Clinic** is a free service set up in partnership with the Legal Advice Centre at the University of Manchester. It is the first holistic clinic of its kind in the country to offer free legal and communication support to those living with dementia and their carers. One-to-one consultations via Skype are available for people living with dementia and their families to discuss personal circumstances, and receive legal advice from professionals.

**As part of a dementia-friendly city, the Mayor should work with London’s universities and law firms to explore the possibility of providing a London Dementia Law and Advice Clinic, similar to the service run in Manchester.**

“When someone in your family is diagnosed with dementia, you move into a parallel world. Everyone treats you a bit differently. Relationships change. You are still part of that world, but everything is slightly different.”

*Family carer, YOYO peer support group*

## Young-onset dementia

May 2018

### ...but there is not enough awareness of how dementia affects younger people

A lack of awareness of the different symptoms caused by different forms of dementia is a particular challenge for younger people. Combined with a lack of recognition that dementia can affect younger people, misunderstanding is widely reported.

Dementia is a feared condition, and people living with it report significant levels of stigmatisation. 2016 research by the Alzheimer's Society shows that almost two-thirds of people surveyed (62 per cent) felt a diagnosis would mean their life was over. 49 per cent worried people would think they were 'mad'. Over half (58 per cent) of people think a dementia diagnosis means no longer enjoying the things they used to, and 68 per cent think they would 'no longer be the same person' if they were to be diagnosed with dementia.<sup>5</sup> The Society reports that too many people feel that a dementia diagnosis means someone is 'immediately incapable of living a normal life.' The idea that 'nothing can be done' to help people with dementia live active and meaningful lives often leads to hopelessness and frustration. Dementia is also frequently (and incorrectly) associated with mental illness, which is itself a stigmatised condition. For people with young-onset dementia, stigmatisation can be compounded by the strong association of dementia with old age. In addition, they may also be navigating environments and services (such as workplaces and childcare) which have very little or no awareness of the need to be dementia-friendly.

'They need to hold a card explaining that they have a language form of dementia, because the typical reaction they get from people is that they are drunk, because they are slurring their words'  
*Professor Sebastian Crutch, UCL*

dementia can do, rather than reinforcing messages that people with dementia are helpless. **The Mayor should ensure that promotional work around dementia-friendly London is reflective of people with young-onset dementia, and of different types of dementias. Work to tackle stigmatisation should include positive role models of younger people who are living well with dementia.**

Action towards a dementia-friendly London will need to balance raising awareness of the factors that can raise the risk of young onset dementia (such as excess consumption of alcohol) with the need to ensure that people with the condition are not stigmatised, blamed or simply disbelieved when they disclose their diagnosis to others. There also needs to be clear emphasis on what people living with

'Before I was diagnosed I would hear, "It is only older people who get this condition". Every time you go, they dig their heels in to say, "It is just older people," and I get so frustrated'

*Person living with YOD*

## Young-onset dementia

May 2018

### Health services need to be more aware and inclusive of younger people with dementia

People living with YOD report significant frustration engaging with services – including health and care services – which do not recognise or accommodate their specific needs. Even getting a diagnosis can be a significant challenge, particularly for those with more ‘atypical’ symptoms such as spatial or language problems which can be confused with other conditions.

Achieving timely diagnosis of dementia results in more effective care and support. However, for all ages, dementia diagnosis rates<sup>6</sup> for all ages in London vary significantly: from between 59 per cent (Havering) to 91 per cent (Islington).<sup>7</sup> Diagnosis rates for people with young-onset dementia are not routinely captured, but NHS England (London region) suggests that for people with YOD, there is often a delay to diagnosis. They suggest this is on average twice that of those with late onset disease, and that on average, each younger person sees between two and five different consultants before a diagnosis is made.<sup>8</sup> The average time between symptom onset and receiving a diagnosis of young-onset dementia is 4.4 years.<sup>9</sup>

Because the statistics are not routinely captured, while dementia diagnosis rates for London are improving overall, it is unclear whether this is true for people with YOD. And there is a significant research gap around the impact of ethnicity, socioeconomic status and health

inequalities on the prevalence of young-onset dementia in London. Existing epidemiological studies are over 15 years old and London’s population demographics have changed considerably in this period. The Dementia Clinical Network NHS England (London Region) has indicated that mayoral support for more research into these issues would be welcome and help the NHS to plan and tailor better services.<sup>10</sup>

Post-diagnosis, there are few dedicated services for people with YOD in London. Dementia services of any kind are variably distributed across the city. The Dementia Clinical Network NHS England (London Region) is currently mapping what services are available where, but at present, there is little information available to people living with YOD, their supporters or even their clinicians, to enable people to be signposted to age appropriate services. NHS England recommends that every person living with dementia has a care navigator to assist them, but notes that this is not happening across London at the moment and there is ‘huge variation.’<sup>11</sup>

There are pockets of good practice in London. People living with YOD highlighted the work of the Merton dementia hub, St George’s Hospital in Tooting, and the UCL Dementia Institute. But there are also concerns that new local projects which work specifically with younger people are often small budget, short-term programmes that disappear when the funding stops. A national survey of people with young-onset dementia in 2017 concluded there was a lack of resources and the absence of policy targeting the rights and needs of younger people living with dementia.

## Young-onset dementia

May 2018

This, combined with a small evidence base on effective interventions, has contributed to the disbanding of specialist services and loss of specialist expertise.



*The YoYo support group in Haringey*

'Getting support after diagnosis I can assure you is essential because I did not have any. I can tell you that if you do not have any, it is absolutely crushing'

*Person living with YOD*

For many people living with long-term conditions such as dementia, ongoing support is often found through the voluntary and community sectors. The Mayor's Health Inequalities Strategy states that this sector needs to be recognised as an integral part of London's health and care landscape. People living with YOD particularly highlighted the value of peer support in learning how to adapt to life after diagnosis. There are a number of peer support groups operating in London. These groups highlight that local neighbourhoods and communities should be the root of a dementia-friendly London. However, we also heard that creating

opportunities for peer support across wider geographical networks through the use of basic phone and online technology could enable more people to access this type of support. This may also allow for more regular contact and continuity of support, which was highlighted as an important element of ongoing support.

'The critical thing people ask for is 'I want to meet other people who know what it is like'. That is often not a professional. It is someone who is living at a similar stage [...] who has been down that road before. For a lot of people, it doesn't matter whether they are in Gloucester and you are in London'

*Professor Sebastian Crutch, UCL*

London has a role to play as the national capital in acting as an exemplar for other towns and cities across the UK. **As part of dementia-friendly London, we would like to see the Mayor commit to working with counterparts in other metropolitan centres and the wider third sector to share best practice and support a national network of peer support for people with YOD.**

'I would be very happy, while I can, to help others do what they want to do. We all have different skills and interests and it is important to keep them for as long as possible whilst also helping each other'

*Person living with YOD*

## Young-onset dementia

May 2018

### Transport is one of the biggest challenges for people living with young-onset dementia

Transport is key to enabling people with dementia to live independently and reduce social isolation. Younger people with dementia may need to continue to commute to work, as well as using transport to access health and leisure services. This means they may be more likely to need to use services at peak times, which can make it more difficult for staff to recognise the need for, and to offer, individual support. Ensuring that services are widely accessible is therefore key. People living with YOD highlighted a number of issues across all forms of transport in London, including the street environment.

#### Buses

Younger people living with dementia told us that more needed to be done to train bus drivers about dementia awareness, and specifically YOD awareness. TfL is rolling out dementia training to its own staff, but it is not clear whether this will apply to bus drivers, who are employed by bus companies rather than TfL directly. **As part of a dementia-friendly London the Mayor should press all bus companies operating within London to implement dementia awareness training, including specific information on young-onset dementia.**

'I can't remember any bus numbers so do not know which one to get. Unless I am with someone, I don't know where to get off. Trying to find anywhere new is very tough'

*Person living with YOD*

People with YOD told us that the variety of routes, destination and interchange points can make the bus network confusing. The London Assembly Transport Committee has previously suggested that bus routes serving particular corridors could be colour-coded like Tube lines, helping people to understand the network and where they can interchange between corridors.<sup>12</sup> Feedback on local trials by TfL suggests that this, and other changes such as putting key destinations on the side of the bus, along with audio and visual stop information, may benefit people with YOD navigating the bus network. **TfL should invite further feedback on these changes from people living with dementia of all ages and, if successful, publish a timetable for rolling this out across London.**

#### Tube/Train

People with YOD reported mixed experiences of travelling by Tube and train in London. Some described positive interactions with staff who helped them to navigate the service and general improvements to wayfinding, particularly at newer stations. But some highlighted difficulties with older stations, especially interchanges including Paddington, and with atypical situations, such as evacuations. They also highlighted additional challenges during station refurbishment and reconfiguration, and when staff were unavailable to offer assistance. **TfL should work with people with YOD and their supporters to work out a timed programme for making priority locations (such as major stations and interchanges) dementia-friendly.**

## Young-onset dementia

May 2018

### Taxi/private hire

Because people with YOD can find other forms of public transport inaccessible to them, taxis and minicabs are seen by many as a lifeline for independent travel. However, this can be an expensive option. Subsidised schemes such as Taxicard are intended to help people with mobility impairment, but there appears to be little recognition that progressive cognitive conditions like dementia can lead to mobility impairment. **As part of a dementia-friendly London, the Mayor should work with both TfL and London Councils to ensure that eligibility for subsidised travel recognises the impact of cognitive impairment on ability to travel.**

### Street environment

As different forms of dementia can affect people differently, there needs to be a wider understanding of how to make street environments more dementia-friendly. People with memory problems told us they appreciated the increased presence of maps to help them find their way around; but those with other symptoms, particularly those affecting vision, told us that more could be done to make street environments more navigable.

‘Crossing the road is quite complex anywhere, especially London. All the crossings should have an alarm to indicate that it’s safe to cross. Sometimes I don’t always trust my eyes as my brain changes what I see, not what I hear’

*Person living with YOD*

### Raising awareness of available assistance

Concerns about asking for help were highlighted as a reason that people with YOD were reluctant to use public transport. TfL has assistance programmes in place to support people to use the public transport network. However, it appears that awareness of these initiatives is limited. People with YOD told us they were unaware, for example, of the TfL travel support card. This summarises useful information on the support individuals need and can include emergency contact details. **As part of dementia-friendly London, TfL should look at how it can work with NHS and voluntary sector services to promote the use of the card to people with YOD. This could also help to raise wider awareness among TfL staff and the public that dementia affects people of all ages and can present with different symptoms.**



TfL is making good progress on making its services more dementia-friendly, but it is clear that more needs to be done to overcome perceptions that using public transport will be a difficult experience for people with ‘invisible’ conditions. It is important that people with YOD are included

in the evaluation of TfL’s programmes to make sure that they are actually reaching the right people and having the desired outcomes.

## Young-onset dementia

May 2018

### Younger people living with dementia need more support to stay in employment

A dementia diagnosis doesn't necessarily mean a person can no longer do their job. With the right support from employers, many people with YOD can stay in employment. This has benefits to the individual, their families, the organisations and to wider society. Eventually, people may need information from their employer about leaving work. This might include discussing early retirement options and access to financial advice. Similarly, support will be needed for those who decide they no longer want to work following a diagnosis of dementia. Currently, around one in five people diagnosed with dementia under the age of 65 continue to work after diagnosis.<sup>13</sup>

Although a hidden issue in many workplaces, dementia is not something organisations can ignore. The Equality Act (2010) requires employers to make reasonable adjustments to ensure people with dementia are not disadvantaged in the workplace. However, a lack of understanding about how to make

*'To carry on doing the things that keep me being healthy and keep my brain working would probably end up using a lot less money than the care I may need if I have depression or other illnesses brought on by my inability to live well'*

*Person living with YOD*

the right adjustments for people with YOD means that for too many, diagnosis is the first step towards unemployment and financial hardship.

The committee has recently looked at the issue of workplace health in London, identifying that autonomy, the opportunity to engage in meaningful activity, and a sense of being valued by an employer are critical to individual wellbeing. This is as true of people living with YOD as it is of any other employee. But, as with many workplace health initiatives, it can be difficult for smaller businesses to access the advice and resources they need to support their workers.

Employment support for carers of people with YOD is also important. Our recent survey found that only around half of employees in London believed that their employer would be flexible if they needed to change their hours to care for a family member.<sup>14</sup> Results were lower for women, those in lower income roles and those in the 55-64 age range. Given that these groups are more likely to be in caring roles, this indicates a need for London employers to provide more reassurance that they will support families of people living with YOD.

**As part of dementia-friendly London, the Mayor should work with dementia organisations to produce updated guidance on how different types of businesses can support employees with dementia and their families. This should be incorporated into the Mayor's Good Work Standard and the London Healthy Workplace Charter.**

## Young-onset dementia

May 2018

### A more diverse approach to cultural and social inclusion for people living with dementia

There is increasing recognition of the positive role that social and cultural activities can have in helping people with dementia to live well. The Mayor's recently published social integration strategy recognises the importance of active citizenship and addressing barriers to participation. However, we heard that much of London's current dementia-friendly social and cultural offer is geared towards a narrow demographic and narrow assumptions about what people with dementia want to do.

'Many people travel to London to see shows or go to the cinema. It would be good if the showings were dementia friendly. I don't want to see Wizard of Oz or The Sound of Music. I want to see modern films'  
*Person living with YOD*

While it is encouraging that more of London's cultural spaces are recognising the value of becoming more dementia-friendly, people living with YOD told us that there needs to be far greater variety in what is made available, otherwise efforts appear tokenistic. Recognising that people with a dementia diagnosis do not stop having an individual personality, culture identity, gender identity, sexual orientation, religion or any other characteristic is critical to designing more socially inclusive cultural offers.

'Making use of what people want to do, their continued passions, their continued desire to be people with a today and a tomorrow, not just a yesterday'

The Mayor has recently launched a consultation on a new Culture Strategy for London. This is a timely opportunity to create links between culture and health services, to the benefit of both. Many of London's smaller cultural spaces are under-appreciated and under-used. By encouraging these spaces to pioneer a wider range of dementia friendly activities there is potential to both promote and embed these cultural spaces within local communities and broaden opportunities for people with dementia of all ages to participate more in community life. **We call on the Mayor to highlight this issue in the final Strategy.**

Small adjustments, such as having identifiable staff trained in dementia awareness, can have a big impact. Dementia Friends training by the Alzheimer's Society is a widely recognised and supported initiative, although some people with YOD have suggested that more specific awareness raising on the varying forms of dementia in younger people might be beneficial.

"Dementia support group and peer to peer meetings don't have to happen in a horrible, dry, clinical space with wipeable surfaces... they need to be happening in warm, inviting spaces in London which during the day are frequently grossly under-used"

## Young-onset dementia

May 2018

### Involving people with YOD and their supporters in shaping a dementia-friendly London

The Mayor has set out plans to make London a dementia-friendly city by 2020. Many of the major challenges, such as ensuring that there is an adequate supply of dementia-friendly housing, or improving the design of London's urban environment, will need to take place over a longer term. Listening to the experiences of people living with YOD and enabling them to contribute to and evaluate the efforts of this initiative will be vital. The Mayor should commit to regular dialogue with groups supporting specifically younger people with dementia, to ensure that his plans are widely inclusive. **As part of a dementia-friendly city the Mayor should consider establishing a citizen's panel on dementia to feed in views as the initiative progresses. People with YOD should also be invited to help support the development and delivery of the London Plan and the Mayor's Transport Strategy.**

But small changes can have a big effect on people with YOD going about their daily lives. People with YOD highlighted that City Hall itself is not a particularly dementia-friendly building, singling out signage and lighting in the public areas as a particular concern. **As a first step towards demonstrating leadership on this issue, we suggest that the Mayor invites people with YOD to audit City Hall as a dementia-friendly building and make suggestions on how to improve this.** This would be a

welcome sign that the Mayor is serious about ensuring people with YOD can participate as active citizens.

#### Next steps

**The committee would like to place on record its thanks to all individuals and organisations who have contributed to its investigation. We are particularly grateful for the contributions of people living with young-onset dementia in London and their supporters for their valuable first-hand evidence.**

The committee will continue to monitor the Mayor's efforts towards developing plans for a dementia-friendly London to ensure that due consideration is given to the needs of younger people.

We will also press for mayoral policies around transport, employment, planning, culture and social inclusion to reflect the needs of younger people living with dementia and their carers.

If you have any further views on how to make London a dementia-friendly city for people of all ages please do get in touch with the committee via [healthcommittee@london.gov.uk](mailto:healthcommittee@london.gov.uk)

## Young-onset dementia

May 2018

### About the Health Committee



The Health Committee reviews health and wellbeing across London, with a particular focus on public health issues and reviewing progress of the Mayor's Health Inequalities Strategy.

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As well as examining the Mayor's actions and decisions, Assembly Members act as champions for Londoners by investigating issues that are important to the capital.

Assembly investigations are carried out by cross-party committees which cover vital areas like transport, policing, housing and planning, the economy, health and the environment. The Assembly can press for changes to national, Mayoral or local policy.

### Endnotes

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<sup>1</sup> The age 65 is used because it is the age at which people traditionally retired; however, this is an artificial cut-off point as opposed to having any biological significance.

<sup>2</sup> Laura Cook, Quality and Improvement Manager, Dementia Clinical Network, NHS England (London) speaking to the Health Committee 28 February 2018

<sup>3</sup> <https://www.youngdementiauk.org/young-onset-dementia-facts-figures>.

<sup>4</sup> <https://www.youngdementiauk.org/young-onset-dementia-facts-figures>

<sup>5</sup> [https://www.alzheimers.org.uk/news/article/64/over\\_half\\_of\\_people\\_fear\\_dementia\\_diagnosis\\_62\\_per\\_cent\\_think\\_it\\_means\\_life\\_is\\_over](https://www.alzheimers.org.uk/news/article/64/over_half_of_people_fear_dementia_diagnosis_62_per_cent_think_it_means_life_is_over)

<sup>6</sup> Diagnosis rate is calculated by dividing the number of people diagnosed with dementia (as reported in national health statistics) by the total estimated number of people living with dementia

<sup>7</sup> <http://www.londonscn.nhs.uk/wp-content/uploads/2018/04/dem-diagtable-mar18.pdf>

<sup>8</sup> <https://www.england.nhs.uk/blog/tackling-the-challenges-of-young-onset-dementia/>

<sup>9</sup> <https://www.rcpsych.ac.uk/pdf/Janet%20Carter.pdf>

<sup>10</sup> Dr Jeremy Isaacs, Deputy Clinical Director, Dementia Clinical network, NHS England (London) speaking to Health committee 28 February 2018

<sup>11</sup> Laura Cook, Quality and Improvement Manager, Dementia Clinical Network, NHS England (London) speaking to the Health Committee 28 February 2018

<sup>12</sup> [https://www.london.gov.uk/sites/default/files/bus\\_network\\_report\\_final.pdf](https://www.london.gov.uk/sites/default/files/bus_network_report_final.pdf)

<sup>13</sup> <http://www.acas.org.uk/index.aspx?articleid=5429>

<sup>14</sup> Populus survey of workplace health commissioned by the London Assembly Health Committee September 2017.