

MAYOR OF LONDON

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Thank you for your letter of 25 May enclosing the London Assembly Health Committee's report on Young Onset Dementia (YOD).

I would like to start by thanking you and the Committee for your work in this area and agree with the conclusion that there is more we can all do to support people with young onset dementia to live well. As you state in the report, I fully support the Alzheimer's Society's vision of a Dementia Friendly London and will use my leadership and influence to help London become the world's first dementia friendly capital city. I have included the initiative in my London Health Inequalities Strategy (London HIS) and the Alzheimer's Society have seconded a senior member of their team to lead the work who will work closely with my health team on this.

Below I set out my response to the specific recommendations in your report:

Raising awareness of how dementia affects young people and access to the right information at the right time

- **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.**
- **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.**

The Dementia Law and Advice Clinic in Manchester led by volunteers at University of Manchester working closely with the voluntary and community sector, is an example of an innovative solution that I would like to see explored in London. My Health Team will convene a meeting of London universities, law firms and the voluntary and community sector to explore a London model for provision of legal advice to those affected by YOD.

As part of my commitment to Dementia Friendly London, I have committed to City Hall and our staff to becoming dementia-friendly. The Alzheimer's Society is supporting the Greater London Authority (GLA) and the Assembly; and I will promote the Dementia Friends programme across the GLA and encourage staff to become Dementia Friends.

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I will ask the Alzheimer's Society to ensure that promotional work around Dementia Friendly London is reflective of people with young-onset dementia, and of different types of dementias. I will also ask that processes are put in place to involve people with YOD and other types of dementia in the programme, as both role models and to advise on the programme.

I will call on others across London to promote the Dementia Friends programme across their organisations and encourage their staff to become Dementia Friends.

Health services

- **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.**

You rightly cite the importance of three key issues in relation to health services:

- The wide variation in diagnosis rates and post-diagnosis support across London
- The need for further epidemiological research
- The importance of peer support and the role of the voluntary and community sector in supporting people with YOD to live well and ensuring everyone with dementia has a named coordinator of care

I will support the Dementia Clinical Network to convene London's research community to identify what research would be most helpful and where myself and others can best support that to happen. I will also ask the Dementia Clinical Network to systematically bring together good practice across London, like the St George's Hub example cited in your report, and that they consider how this kind of example could be offered routinely across London in way that is sustainable. Through the implementation of the London HIS, I will ensure that people affected by all types of dementia are included in efforts to increase levels of peer support and social prescribing.

Transport

- **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.**
- **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.**
- **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.**
- **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.**
- **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.**

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I am pleased that your report recognises the good work that Transport for London (TfL) is already doing. Both they and I recognise there is more to do. TfL has identified bus companies as a key element of their strategy. I understand that discussions are underway between TfL and the bus companies towards drivers becoming more dementia aware. I will request an update on these discussions and your proposal that they invite further feedback on the suggestions from the Assembly Transport Committee around signage and wider information provision along with working towards an action plan for priority dementia-friendly locations.

I will ask TfL to actively explore how it will Design for the Mind, and ensure future plans for street, station, interchange and other modes of transport, are designed more appropriately for people with cognitive conditions.

My Health Advisor, Dr Tom Coffey, will raise the issue of including cognitive impairment within the eligibility criteria for subsidised travel with London Councils, involving TfL colleagues as needed.

I will ask the Alzheimer's Society to work with partners including the NHS, the voluntary and community sector and TfL on how best to promote assistance programmes such as the TfL travel support card.

Support to stay in employment

- **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.**

For many people employment is a crucial part of their lives and their sense of self-worth and contribution to London life. It is also important in providing economic security for themselves and their families. Whilst there are some employers doing well in this area, for example Sainsbury's, there is a need to increase awareness. The Alzheimer's Society already produces a range of guidance for employers, which includes reference YOD. I will check with them whether further materials are needed and whether small businesses are adequately reflected. I will also make sure that advice and guidance on YOD is included in my Good Work Standard and the London Healthy Workplace Charter and this will cover people directly affected as well as carers.

As you are aware from the Dementia Friendly London Summit in May, the Confederation of British Industry in London is supporting the campaign, and I will work with them to find and share examples of good practice and to increase awareness of YOD across London's business community.

Cultural and social inclusion

- **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.**

Health does not happen in a vacuum. It is intrinsically linked to our environment and the way we live our lives. Opportunities for cultural enrichment and to connect with others can both improve our lives. A lack of these opportunities has a negative effect on health, both mental and physical. I

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will ensure that the Culture Strategy and London HIS are linked, and that the Culture Strategy promotes good health and that the London HIS encourages engagement in cultural activities. Social prescribing, including to cultural activities, is a key commitment in the London HIS.

I will help promote use of the Alzheimer's Society *Side by Side* programme and encourage people to become *Side by Side* volunteers. This programme matches up people with similar interests to support people with dementia to continue to do the things they love. I will promote volunteering opportunities through Team London.

Empowering people with young-onset dementia and their families

- **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.**
- **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.**

Meaningful involvement of people affected by dementia is a core principle of Dementia Friendly London. I will consider your recommendation to establish a citizen's panel to feed in views as the Dementia Friendly London initiative progresses, including people with young-onset dementia. I will seek advice from the Alzheimer's Society on the best way to proceed utilising the existing groups at London and local level. I will be steered by the Alzheimer's Society on this, but would expect their strategy for involvement to include a range of standing groups and regular dialogue with a wider range of organisations including early-onset groups.

The GLA has established a City Hall Dementia Friendly London working group with Transport, London Plan and Facilities Management teams all represented. I will work with the Alzheimer's Society to involve people affected by dementia in the work of the group and get their input into City Hall building and processes and strategy and implementation.

Thank you for your Committee's thorough report on Young Onset Dementia; it will strengthen the Dementia Friendly London initiative. I would also like to thank members of the Committee and the rest of the Assembly for continuing to champion everyone affected by dementia.

Yours sincerely,



Sadiq Khan
Mayor of London