

# Living with Dementia in London 2023



## Dementia

*Dementia is a condition that affects the brain and can cause a decline in cognitive function and the ability to carry out daily activities. Dementia is not the same as memory loss. It is the leading cause of death in the UK and is becoming more prevalent, particularly among younger people.*

## Integrated Care Systems

*An Integrated Care System (ICS) is a system that brings together health and care organisations in a particular local area to work more closely together. Integrated Care Systems were established as legal entities in July 2022 and are responsible for planning health and care services in their area.*

**Our evaluation of dementia services for the Integrated Care Systems revealed a fragmented and unsatisfactory experience for the almost 73,000 people in London with dementia and their carers. While pockets of good practice were identified, they were often overwhelmed by demand and a lack of provisions in neighbouring boroughs. Those living with dementia often felt “ignored” and “disrespected”. At the same time, carers struggled with the emotional and physical impact of caring for someone with dementia and the administrative burden of an uncoordinated health and social care system.**

## Positive experiences

People living with dementia and their family and carers appreciate the hard work done by experienced individuals or teams who want to make a difference. Carers centres and charities help connect peers and provide a supportive network to resolve issues. People appreciated having support within their own homes and in their language. People felt secure when taught more about dementia, their rights, and options for supporting people living with dementia.

## Challenges

Although they had received a diagnosis of dementia, more than three-quarters of people (77.4%) were unfamiliar with national dementia guidance. Nine out of ten carers (93.8%) were not offered a coping strategies intervention after their loved one was diagnosed.

Despite London’s multicultural makeup, we did not find one person who had been provided information in a language other than English.



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Many were concerned about carer burnout. They felt the need for therapy to help those living with dementia and their carers when they transition to cope with the condition's demands. The dementia pathway was often unfavourably compared to other health conditions. People feel that GPs and social services are described as "unreachable" and "unsympathetic". Systemic issues were also identified, such as a lack of good leadership within health and social care settings, few agreements between health and care providers to share information, and inadequate staff training.

There is a need for better coordination between health and social care services for people with dementia. Participants in the evaluation noted that health and care providers were hard to make contact with and worked in silos, with few data sharing protocols or inadequate training for even staff dedicated to supporting people with dementia.

## What do people want?

Despite all the problems people living with dementia face, what we found they wanted was realistic, practical and achievable. People living with dementia want to live as independently as possible in their own homes. They would like annual health checks, a personalised plan with guidance in their language, and someone they can call for advice.

Many found it hard to take on board the information they received at the point of diagnosis, so it was recommended that a review is conducted six months after diagnosis. This would then be followed by an annual review. These reviews would include:

- An interview with family or carers,
- A discussion of any concerns,
- A medication review,
- Sight and hearing checks *and*
- Signposting to local support services.

The reviewer would be a professional with experience in dementia, and the output of the review would be a care plan that could be shared with other professionals.

People also wanted someone who could support them with administrative tasks, involvement in research, opportunities for therapy, and more training.

## Conclusion

The evaluation of the London dementia offer carried out by Care City highlights the need for better coordination and communication between health and social care teams, as well as the need for more comprehensive training and awareness among care providers.

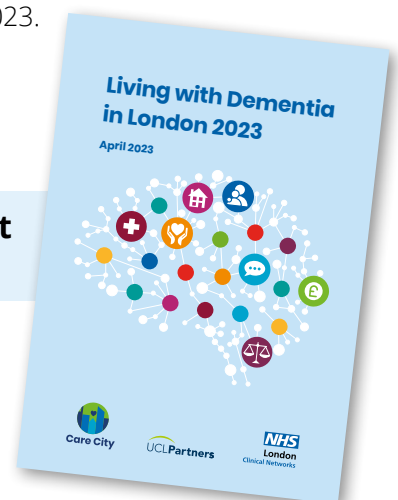
The report also emphasises the importance of early intervention and support for people living with dementia and their carers, including in-person reviews, access to counselling and therapy, and assistance with financial and legal issues.

Additionally, the report calls for more involvement of people living with dementia and their carers in research and advocacy efforts. Overall, the report highlights the need for a more consistent and compassionate approach to dementia care in London.

## What's Next?

Based on the report the London Clinical Dementia Network will pilot a framework to introduce annual health checks and reviews. The results will be published and shared in 2023.

**Read the full report  
HERE.**



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