

Patients, carers and friends and family's views contribute to defining Croydon's new dementia strategy

Press release: 23 June 2023

- Healthwatch Croydon presents the final report on *Dementia Pathway Experiences in Croydon*, informing the Croydon Dementia Strategy through insightful surveys with patients, carers, and friends/family, in collaboration with the Alzheimer's Society.
- Issues raised include diagnosis time, post diagnosis support, support and care needs, advance care planning, information services for both patients and carers, understanding needs and preferences, as well as suggested improvements, concerns about going into care home and hospitals and what contributes to making Croydon dementia friendly.
- Recommendations included better communication and information, improving the time for diagnosis, care planning and reassessments, increased carers support, understanding needs and preferences, and better awareness. These have informed the Croydon Dementia Strategy due to be published later this year.

KEY OBJECTIVES AND BACKGROUND

Healthwatch Croydon partnered with the Alzheimer's Society to receive views and experiences on dementia pathway services in Croydon. The objective was to gather valuable input to inform the development of a new dementia strategy for Croydon. Healthwatch Croydon undertook three online surveys, engaging patients living with dementia, their carers, and friends and family members. By aligning the survey questions, a comprehensive analysis of experiences across different cohorts was made possible.

The Alzheimer's Society played a crucial role in recruiting participants through their extensive networks, while Healthwatch Croydon took charge of data analysis and presentation. The surveys garnered responses from 19 dementia patients, 41 carers, and 20 friends and family members. The questions covered various themes, including diagnosis, information and support, suggested improvements to services, and the concept of being dementia friendly.

FINDINGS

Issues around diagnosis: The length of time to see a specialist is an issue for all but particularly with carers. More patients felt they could manage but others do not. High level of denial particularly for carers. Friends and family felt it was part of getting older.

After diagnosis: There is a need for a better information and communications. Better information needed on legal and financial entitlements and improved communication on support services.

Carers support and information services: Despite these services being available, many carers need easier ways to be access information and support they need.

GP follow up appointment: Greater awareness of follow up appointment is needed with over half stating they did not have it or did not know which levels higher for carers and friends and family.

Discussion of support and care needs: Patients and friends and family do feel there has been a discussion, but carers felt they did not, and friends and family could have more.

Advanced care planning: It not being provided or accessed effectively even though it should be offered after diagnosis and each review.

Appropriate services to needs and preferences: There is a need for more understanding of services appropriate to their needs for patients maybe with better coproduction with patients, carers and family and friends.

Reassessment of dementia and care needs: There is a need to look at the low accessibility or uptake in dementia or care need reassessments.

Improvements: Patients would like to see words put into action, good support when leaving hospital and less variability in the quality of home help. Carers would like time for a break, support within the home and day centres. Friends and family also would like to see more home help, more day centres and that they are being listened to.

Concerns about sheltered accommodation and care homes: Patients said they would be too restrictive with loss of freedom, lost possessions when put in storage, others just never want to go. Carers want to ensure care come is adapted to come with dementia and understand what patients need, as well as being nearby to where they live, having an activity programme and good well-paid staff who have respect for the person. Friends and family want to be able to choose home with a good CQC rating, as well as help as finances.

Concerns about going into hospital: Patients said a need to ensure that dementia patients have a dedicated pathway if going into hospital ensuring they have the specialist support they need with these issues considered. Carers need to be easily identified as advocates. Being discharged with the right support is also an important priority.

Making Croydon dementia friendly: Patients say this is creating a choice of activities, increased understand and education. Carers say this training for services and retailers, education, quiet spaces, and information. Friends and family also talk about greater understanding and providing services that are theoretically possible.

RECOMMENDATIONS

Based on the survey findings and insights obtained, we have developed the following recommendations for the Dementia Project:

Communications and information

- Better information needed on legal and financial entitlements and improved communication on support services and after diagnosis.
- Greater awareness or access to GP follow up appointments, advanced care planning and dementia and care need assessments.

Diagnosis, care planning and reassessments

- **Improve the time it takes to see a specialist Issues around diagnosis.**

Increased carers support

- **Discuss more about support and care needs with carers.**
- **Improve the awareness and communication of carers support and information services.**
- **Find ways to increase confidence of patient and carers to manage the condition.**

Understanding needs and preferences

- **Coproduce services to understand needs and preferences and align services accordingly.**
- **Understand concerns about care homes and sheltered accommodation, particularly around their understanding about dementia, quality of service, staff training, a person-centred approach with residents, access, and support with finances.**

Hospitals

- **Design a dedicated pathway if going into hospital ensuring they have the specialist support they need with these issues considered.**
- **Ensure carers can be easily identified as advocates.**
- **Make sure patients are discharged with the right support is also an important priority.**

Suggested improvements from residents

- **More support, quality of care, information, and wayfinding.**

What makes Croydon dementia friendly

- **Ensure effective support and increase awareness of dementia.**

You can view the report [here>>>](#)

Dr Emily Symington, GP - Parchmore Medical Centre, Croydon, and Clinical Lead - Personalised Care, Population Health Management, Long Term Conditions, Croydon Place, said: “The Dementia & Older Adults Steering Group have found the survey useful to understand the views of people with dementia, their families and carers living within Croydon. We heard about how communication at all parts of their journey was important and how people wanted to be supported and heard by those providing services. The findings have underpinned the development of the Croydon Dementia Strategy which is due to be published later in 2023. The Croydon Dementia Strategy focuses on the diagnosis and support available for dementia; and how to ensure people in Croydon are able to live well with dementia as well as coming to the end of their life well. We have been able to take the different responses and apply these within each part of the dementia pathway, weaving in feedback comments and emphasising the importance of information and support at every stage. As a part of the development process, we have been able to feedback to system partners points about specific services and think about what could be changed to meet the identified needs. Healthwatch Croydon is a valued partner, and we would like to thank Gordon and team for their hard work on this report. We look forward to exploring future possibilities with the Croydon Healthwatch team as we begin to implement the dementia strategy and measure its outcomes.”

Gordon Kay, Healthwatch Croydon Manager, said: “Dementia is a high priority for all health and social care providers. There is an estimated 3,597 people over the age of 65 with dementia in Croydon, and this is predicted to rise to 5,471 by 2039 yet only 2,692 have received a diagnosis. Our partnership work with the Alzheimer's Society to understand experiences of views of patients, carers and friends and families has helped define the soon-to-be publishes strategy and make a difference to all those affected by dementia in the coming years. We have already received positive feedback from key stakeholders. As a member of the Croydon Dementia Action Alliance, we look forward to working with services in the coming years to ensure all the recommendations are implemented.”

Editor's notes

Healthwatch Croydon is here to improve the experience that Croydon people have when they need to use health and social care services. We believe that the best way to do this is by listening to patients and service users.

There is a local Healthwatch in every local authority area in England.

Our role is to make sure that that local health and social care services, and the local decision makers, put the experiences of people at the heart of their care.

We are a statutory body - this means that we have a legal status to exist within the Health and Social Care Act 2012. This means decision-makers should listen to us when we give them feedback and make suggestions.

For more information, please contact: Jeet Sandhu, Healthwatch Croydon Communications Lead jeet.sandhu@healthwatchcroydon.co.uk

Or Gordon Kay, Healthwatch Croydon Manager gordon.kay@healthwatchcroydon.co.uk