



**Dementia carers  
experiences of using  
Croydon's health and social  
care services**

**February 2019**

## Findings in brief

**GPs**

are crucial to carer experience

There is a need for **right support** at the **right time**

**Clear pathways** for support are very important

Experience of NHS quite positive but **inconsistency** between providers

**Social care** advice seems to focus on finances first before care options

Need for a clearer **consistent approach** across services

## Recommendations in brief

Ensure GPs are well trained and compliant with latest national guidelines

Present clear pathway information for support and consistent signposting

Each NHS service to review and look at best practice for dementia patients and carers

Look at customer journey as a whole with an integrated approach

Review social service information and support to focus on care options before considering finances

Continued dementia carer experience monitoring through One Croydon Alliance

# Executive Summary

Dementia is a key issue for Croydon with over 3,611 people aged 65+ said to be living with this condition in the borough and 2,339 registered as having confirmed diagnoses by Croydon GPs in 2017/18. There is the expectation of an increase in people diagnosed in the years to come, due to an increasingly ageing population. This research was interested in collecting the experiences of carers for those with dementia, from diagnosis to information and support as well as the impact of becoming a carer. We received comments from 70 of those caring for people with dementia in Croydon who are actively using services having received these responses.

## These are our findings:

- **GPs are crucial to the experience:** GPs have a critical role in being a gateway to services, so confidence in them diagnosing early and referring patients and carers effectively needs to be good. Nearly 1 in 6 did not feel they had had this experience in Croydon.
- **There is confusion about pathways for support:** Having an understanding of a clear pathway for support is significant in helping patients and carers cope with their situation. Many patients in Croydon were confused about how they accessed the right sources of information and support.
- **Right support at the right time:** Appropriate support at the right time makes a difference to carers and patients' experience. A third of those surveyed felt they did not get what they needed, when they needed it.
- **NHS service experience is mostly positive, but good practice needs to be shared:** A more consistent service experience would be beneficial.
- **Social care advice and support seems to focus on finances first before care options:** Carers felt there was a lack of useful information or help with too much emphasis on financial aspects of providing care and process issues, instead of focusing on the caring and support needs that carers and patients wanted.

These are our recommendations linked to provider and commissioner:

Based on our findings we make the following recommendations for the Croydon Dementia Action Alliance (CDAA), Croydon Clinical Commissioning Group (CCG), GP Collaborative (GPC), Croydon Health Services (CHS), South London and Maudsley NHS Foundation Trust (SLAM), Croydon Council Social Services (CCSS) and voluntary organisations such as Age UK and Alzheimer's Society.

- Ensure all GPs are fully compliant with national guidelines in diagnosis and response times for referrals. (For CCG,GPC)
- Ensure suitable and easy to access signposting for support is available from GP and community level. (For CCG, GPC, CHS)
- Present the appropriate pathways of support and information in clear way which can be easily understood by the carer, perhaps as a leaflet and online material. (For All)
- Each NHS service should review their service delivery where patients with dementia are involved to ensure they meet patient and carer needs at each stage in the customer journey, with an emphasis on working together to deliver a seamless service between providers. (For CHS, SLAM, CCG)
- Review social service information and support to focus on care options before considering finances. (For CCG and CCSS with the involvement of the CDAA)
- Continued monitoring of patient and carer experience by all service providers to see how service experience has changed in previous 12 months. (CHS, GPs, CDAA and Healthwatch Croydon).
- Apply the power of the One Croydon Alliance: One Croydon has the opportunity to bring key parties together to find solutions. The needs of dementia patients and their carers should be high on their agenda to make a more integrated service.

# 1 Background

## 1.1 Context

### About Healthwatch Croydon

Healthwatch Croydon works to get the best out of local health and social care services responding to your voice. From improving services today to helping shape better ones for tomorrow, we listen to your views and experiences and then influence decision-making. We have several legal functions, under the 2012 Health and Social Care Act.


### National level -Dementia

Dementia has been a key priority for some years. In February 2015, the government published a Challenge for Dementia 2020 vision<sup>1</sup>. Some of the key aspirations of this vision were equal access to diagnosis for everyone; GPs playing a lead role in ensuring coordination and continuity of care for people with dementia; every person diagnosed with dementia having meaningful care following their diagnosis; and all NHS staff having received training on dementia appropriate to their role.

Since then, NHS England has focused on developing an appropriate access and waiting time for dementia so people with potential symptoms have equal access to diagnosis as for other conditions; setting the national average for an initial assessment at six weeks; achieving and maintaining the dementia diagnosis rate. NHS England agreed a national ambition for diagnosis rates that two thirds of the estimated number of people with dementia in England should have a diagnosis with appropriate post-diagnostic support. They agreed that the dementia diagnosis rate will be included in the CCG Assessment Framework. In terms of post-diagnostic care and support, NHS England proposed financial incentives to improve this,

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<sup>1</sup> <https://www.england.nhs.uk/mental-health/dementia/>



including a care plan on discharge from secondary care services and increased health and wellbeing support offered to carers.

In addition, there is the development and publication of a 5-year transformation implementation plan called the ‘Well Pathway for Dementia’ which covers preventing well, living well, supporting well and dying well.

Dementia has had a significant mention in the recently-published *Long Term NHS Plan* (2019, p.17-18)<sup>2</sup>:

“One in six people over the age of 80 has dementia and 70% of people in care homes have dementia or severe memory problems. There will be over one million people with dementia in the UK by 2025, and there are over 40,000 people in the UK under 65 living with dementia today. Over the past decade the NHS has successfully doubled the dementia diagnosis rate and halved the prescription of antipsychotic drugs. We have continued to improve public awareness and professional understanding. Research investment is set to double between 2015 and 2020, with £300m of government support.

We will provide better support for people with dementia through a more active focus on supporting people in the community through our enhanced community multidisciplinary teams and the application of the NHS Comprehensive Model of Personal Care. We will continue working closely with the voluntary sector, including supporting the Alzheimer’s Society to extend its Dementia Connect programme which offers a range of advice and support for people following a dementia diagnosis”

In terms of national advice to GPs, *Dementia diagnosis and management- A brief pragmatic resource for general practitioners* (2015)<sup>3</sup>, states a crucial role for carers: “Carers are the most valuable resource in dementia care and we should have a high level of awareness of their needs. Carers may be referred for a carers

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<sup>2</sup> <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf>

<sup>3</sup> <https://www.england.nhs.uk/wp-content/uploads/2015/01/dementia-diag-mng-ab-pt.pdf>

assessment and benefit check. Carers' groups provide support and information.” (p7).

NICE guidelines, *Dementia - assessment, management and support - Involving people living with dementia in decisions about care* (2018) <sup>4</sup> states that:

“Provide good quality, timely information for the person living with dementia can help increase their involvement in key decisions and help them to have a share in the decision-making process... We must ensure that these regulations are used to work for the person living with dementia, not against them. This will often require working closely with other agencies in partnership to ensure the person living with dementia, their families and carers receive high quality support.” (p.125).

### National level - Carers

At a more general level for carers The Care Act 2014 which came into force in April 2015, aims to put disabled people and carers in control of their care and support. It gave local authorities such as Croydon Council a new general responsibility to promote a person's wellbeing when providing support. This includes doing an assessment, creating a care plan and providing practical support. Local authorities must ensure people in their area have accurate information and advice to make an informed decision about care and support. New national eligibility criteria for providing support have been introduced for all local authorities in England. Carers and people who need support have separate eligibility criteria. Carers have the same right to an assessment as disabled people. This means they no longer have to provide a 'regular' or 'substantial' amount' of care to get a Carers Assessment. <sup>5</sup>

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<sup>4</sup> <https://www.nice.org.uk/guidance/ng97/documents/full-guideline-updated>

<sup>5</sup> <https://www.carersinfo.org.uk/useful-information/faqs>





## Local level:

Dementia is a key issue for Croydon with over 3,611 people aged 65+ said to be living with dementia<sup>6</sup> in Croydon and 2,339 having been diagnosed by Croydon GPs in 2017/18.<sup>7</sup>

This health issue led the formation of the Croydon Dementia Action Alliance (CDAA) in March 2017 which is a partnership working to raise awareness about dementia and helping to make Croydon a dementia friendly borough that is inclusive for people living with the condition. Members include voluntary organisations such as Age UK and the Alzheimer's Society, Croydon Mencap, Croydon Voluntary Action, as well as health service providers such as Croydon Health Services, Home Instead and Right at Home domiciliary care services, and One Croydon Alliance. Other active members include the fire brigade and police.

In 2017, the Carers Information Service in Croydon published research *Not Just a Patient*<sup>8</sup> on their carers detailing what they need from their GP stating:

“Overall, carers are broadly positive about the healthcare they receive from their GP, but would like to be informed of carer support available to them. We therefore recommend that all surgeries in Croydon ensure that registered and identified carers are provided with information about the Carers Support Centre, and that carers are referred directly if in need of support.”

In October 2018, the CDAA achieved the highest accolade from the Alzheimer's Society for their work across the whole borough.<sup>9</sup>

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<sup>6</sup> Statistics from Projecting Older People Population Information System (POPPI)  
<http://www.poppi.org.uk/>

<sup>7</sup> Statistics from Quality and Outcomes Framework of NHS England:  
<https://digital.nhs.uk/data-and-information/publications/statistical/quality-and-outcomes-framework-achievement-prevalence-and-exceptions-data/2017-18>

<sup>8</sup> <https://www.carersinfo.org.uk/assets/content/CIS-Not-Just-a-Patient-Report-Full-2017.pdf>

<sup>9</sup> <https://wp.croydon.gov.uk/newsroom/croydon-praised-for-efforts-to-make-the-town-dementia-friendly/>

Healthwatch Croydon have worked with them to scope and define this research.

The South London Sustainability and Transformation Plan (2017) made reference to speeding up diagnosis and treatment for people with Dementia (p76) and the application of the blue band scheme in hospitals which was seen as an excellent tool to help staff be more aware of patients' mental health and take more time when explaining a procedure (p171).<sup>10</sup> More detail is expected to be published the new South West London Health and Care Plan due to be published later this year.

Croydon's Carers Strategy (2017) published in 2017<sup>11</sup> focused on improving support and information available having spoken to a range of carers including 29% who cared for people with dementia. Priorities in the Action Plan (p.39), included: review the provision of respite services in the borough and respond to the changing need of carers; increase the promotion of current services to ensure more carers benefit from them; improve integration of services between health and social care; ensure adult social care provide information packs for carers to include carers information which should be both online and in paper format; Increase awareness of carers in health and social care to ensure carers are identified earlier and involved in discussions, including young carers.

## 1.2 Rationale and Methodology


Our rationale for undertaking this research was to understand more about the issues around accessing health and social care services for people with dementia in Croydon, finding out what they think about existing services explore where there are gaps and know what is working well, to inform commissioners and providers

Due of these factors, Healthwatch Croydon wanted to look more closely at the pathway and identify areas of unmet need and gaps in services.

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<sup>10</sup> <https://www.swlondon.nhs.uk/wp-content/uploads/2017/11/STP-discussion-document-final.pdf>

<sup>11</sup> <https://www.croydon.gov.uk/sites/default/files/articles/downloads/Croydon%27s%20Carers%27%20Strategy%202018-2022.pdf>



Having attended meetings of the Croydon Dementia Action Alliance (CDAA), Healthwatch Croydon considered how it could contribute to their work and suggested that a survey be created about carers experiences of the dementia services in Croydon. The members of CDAA agreed with this idea and advised us on the questions.

The Alliance aims to make Croydon more of a dementia-friendly environment for the borough. It is our aim to understand what residents really think about services, what is going well and what could be better, and then feedback to the One Croydon Alliance.

### 1.3 Method

We took the survey to the elderly wards of Croydon University Hospital and also distributed the survey via the Alzheimer's Society and their carers support groups at Carers Information Centre and at their own cafe events

We circulated the survey on social media and distributed the survey through the Carers Information Centre.

We asked carers and relatives the following:

- **Who did residents turned to with their concerns regarding their relative memory?**
- **Were those concerns taken seriously?**
- **How long before a diagnosis was made?**
- **Did they get the right services at the right time?**
- **Did they get the advice and support they needed?**
- **Who provided the advice and support?**
- **What were their experiences of NHS and Social Services?**
- **What support they would like to see?**

All surveys were filled in on a voluntary basis and some participants did not answer all the questions. We appreciate all the responses we received from carers during what may be a challenging and unsettled time of their life.

We also thank the staff at Croydon University Hospital and the Alzheimer's Society for helping us access carers using their surveys. In total 70 surveys were completed between May and November 2018.

Sources	Number
Croydon University Hospital	18
Smart Survey	14
Survey Monkey	2
Alzheimer's Society	11
Carers Information Service	11
Post- Via Alzheimer's Society	14
	Total - 70

Respondents were encouraged to tell us about the services and are included in the comments throughout this report.

### Thank you

Thank you to Caroline Walker at Croydon University Hospital, Selma Hameed and Sue West at Alzheimer's Society and also Helen Thompson at the Carers Information Centre in Croydon along with their colleagues for their help.

We also thank our Healthwatch volunteers who supported the staff team in collating and analysing the data: Scoping - Gillian Khalighi; Outreach - Carole Hembest, Nick Maffia, Ginikachi Mbakwe, Pauny Ekanga and Brian Matthews; Analysis - Megan Nash.

### Limits of the research

This is a hard-to-reach group. Carers, because their responsibilities spend most of the time, in the home or bedroom, are not easily found in the community. Most carers we spoke to were engaged in services, and it must be said that there are an unknown number of carers who are unheard and coping without help.

The sample is 70 which has limits in terms of statistical significance, but gives a good insight into the issues that carers of those with dementia are experiencing which can be used to improve services.

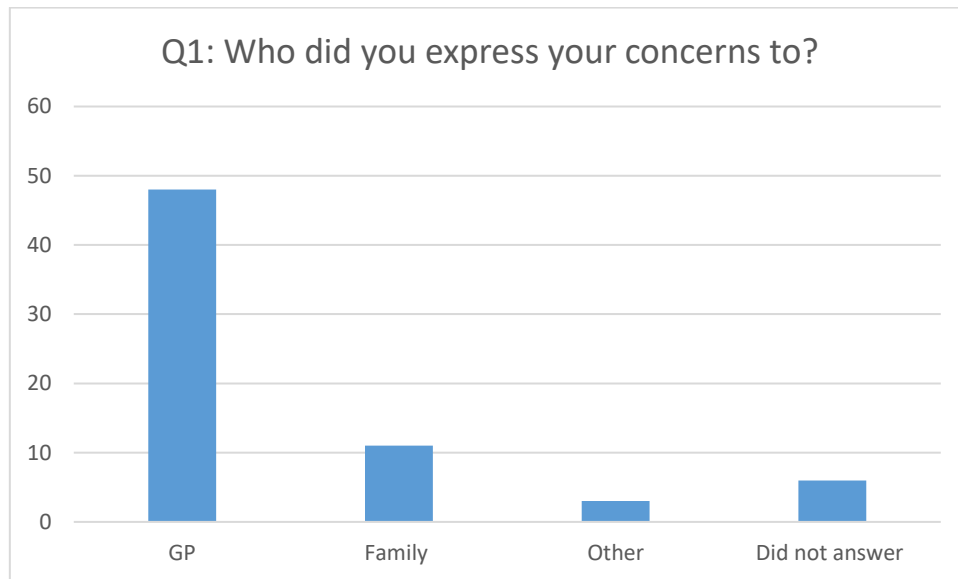
When looking at the NHS, we did not research the different services provided, although experiences of GPs are more defined. More patient and carer experience in specific areas, will add to any further specific future research.

There may well have been confusion by carers on who was responsible for funding and delivering services and this is reflected in some of the responses. For example, Croydon Clinical Commissioning Group commissions the Alzheimer's Society to deliver information and advice services on referral from the GPs, rather than Alzheimer's Society just providing this service independently. Likewise, many carers community services are provided by voluntary organisations like the Carers Support Centre, on contracts from Croydon Council Social Services, who believe that providing that support at that level is more effective than at a central council level. That said, since Croydon Council also provides an information and support service as well only adds to the confusion.

Ultimately, for the service user, it is about the ease, effectiveness and consistency of information that helps define whether they have a positive experience in getting the advice and help they need. This is emphasised in the recommendations.

## 2 Insight results

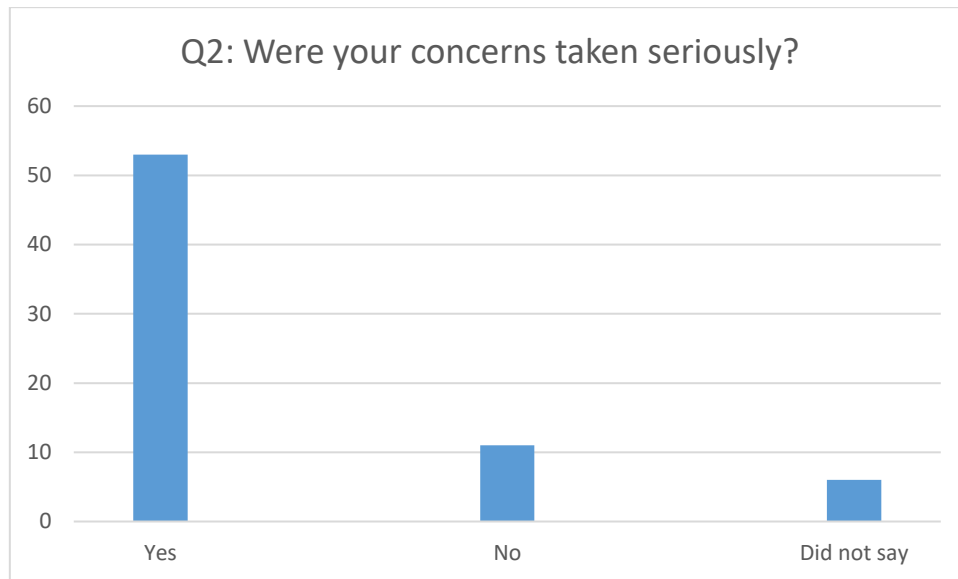
### 2.1 Who did carers first express their concerns to regarding their relative's memory?



Total=68

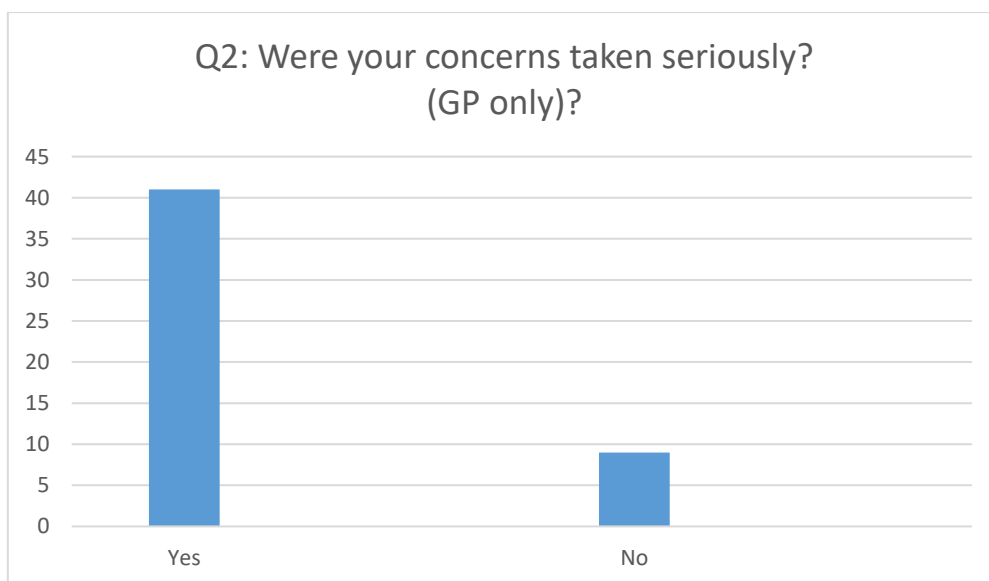
The GP has crucial role that cannot be underestimated, as the gateway to services and referrals, and the first port of call often preceding family and friends that Croydon residents turn to for support. When people had concerns about their memory, the GP was the person that they expressed these concerns to, with 70% people (48) spoke to their GP first, and 16% (11) talking to their family.

## 2.2 Were their concerns taken seriously?



Total=70

At the first stage of diagnosis, having your concerns taken seriously is a key part in having confidence in the health and social care system to meet your needs. Of those asked 76% felt that their concerns were taken seriously, but 16% felt they were not.



Total=50

When we focused on those 50 who consulted their GP, 82% (41) felt that the GP took their concerns seriously but 18% (9) did not. While this number is positive, over one in six still feel their concerns were not considered, so a more consistent approach is needed across GP providers.

#### Carers said:

“Referred to memory clinic straight away.”

“Asked lots of questions, getting to know my husband. Then did a memory test. Very good. After that went for a scan at (the) Maudsley hospital.”

“Immediately taken seriously.”

“(The GP) Listened and dismissed me - (I) felt unsupported.”

“It took a long time to get referred to the memory clinic.”

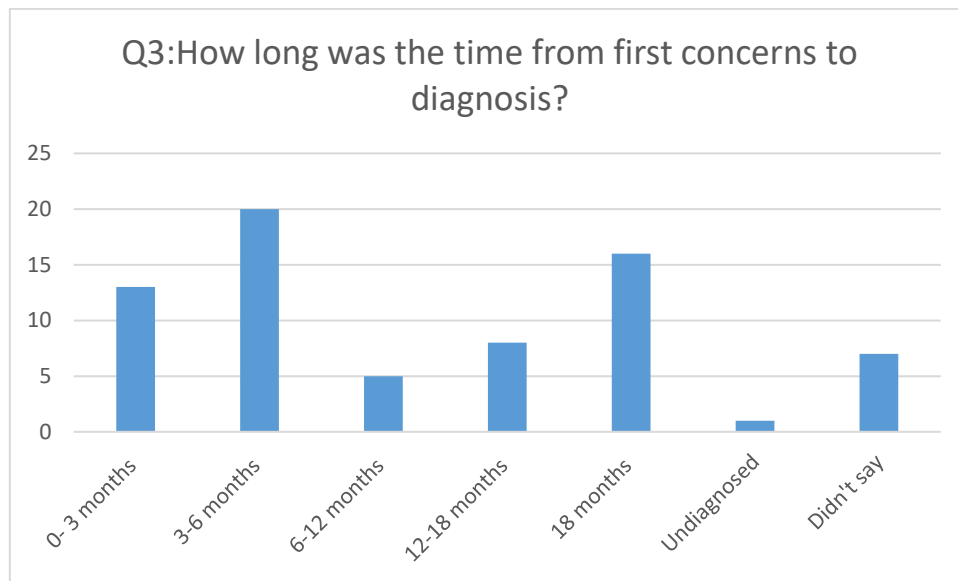
“Eventually, took a while but after resistance they referred us to the memory clinic.”

“(I) wonder if GP is truly aware of signs and indicators.”

“Doctor did test twice but said all OK.”



## 2.3 How long was the time from first concerns to diagnosis?



Total=70

Response times from first concern registered with health professional to diagnosis is a key part in ensuring that services can be provided effectively. Early intervention means better preparation and a more effective care plan can be put in place. This, in turn, reduces the initial concern felt by family and carers.

Where diagnosis was made it was promptly, mostly between 3-6 months, with 48% (33) gaining diagnosis at this time. However, numbers rise again from 12-18 and 18 and above with 34% (23) waiting a year or over. This may be due to them not approaching the right pathway or delays in GP referrals/diagnosis. This is something that needs further exploration.

### Carers said:

“The GP asked lots of questions, getting to know my husband and then did a memory test.”

She wasn't herself...got worse...took about 1 year, care for relative 9-5 paid for by me.”

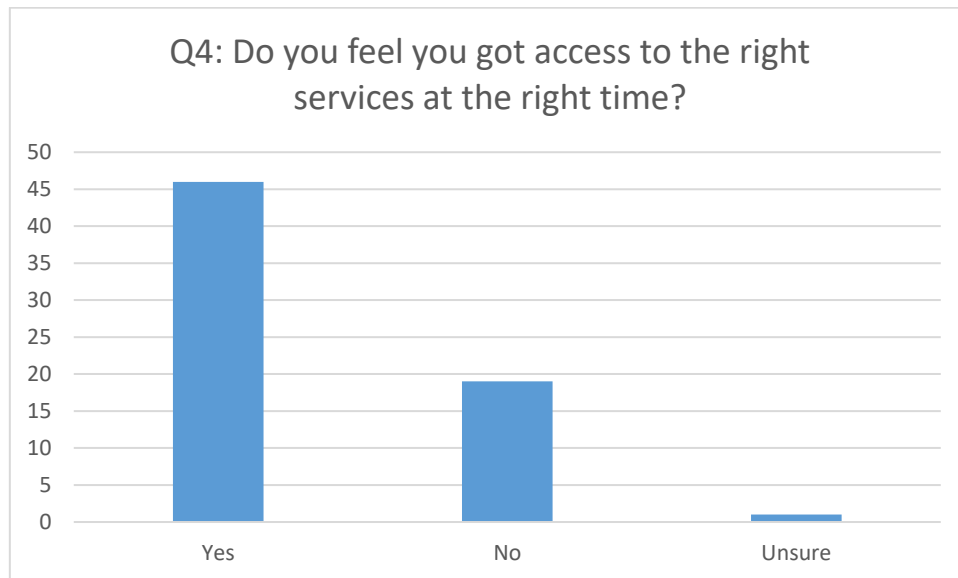
Some were not yet diagnosed, one was admitted to hospital in a serious condition before a diagnosis was made, advised by Alzheimer's Society that CUH did the diagnosis, not knowing before then, and felt they had not been given the right information.

“Been waiting 18 months for diagnosis, in and out of hospital, not getting the right care.”

One carer felt a misdiagnosis of dementia had been made.

“I don't think he had dementia, but he has been diagnosed with dementia.”

## 2.4 Do carers feel they got access to the right services at the right time?



Total=66

Ensuring that carers get access to the right services at the right time, reduced their anxiety about the situation. 70% (46) did feel they got the service their need but 31% (20) did not or were unsure.

It is understandable that there would be a number who did not get access at the right time, as this can vary from a person's specific circumstances to waiting time to gain access.

### One carer said:

“(We) didn’t know what to ask for, a lack of buy-in from the patient and not knowing what’s available.”

### Some carers requested more practical support services:

“I could have done with support, respite for me, I joined the carers community, advice there if I need it.”

“Let them know what is available and for who.”

“I want all my options.”

“Carers need a lot of support, also help with who they are caring for. Waiting all the time.”

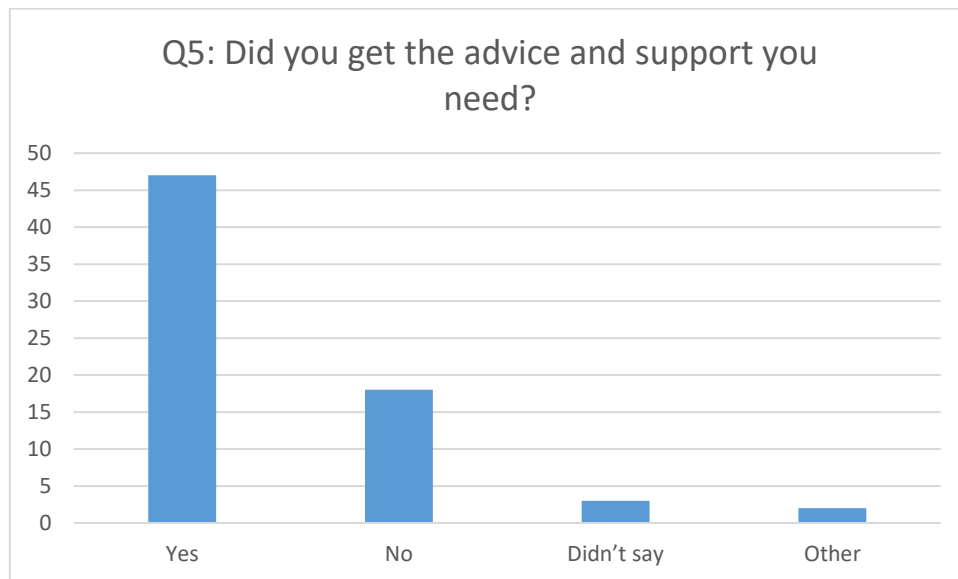
“Not just paper handouts.”

“Support for carers.”

**Regarding the choice of residential care homes, we were told:**

“CQC (reports are) not good, the ones we are offered are not the ones that we want’

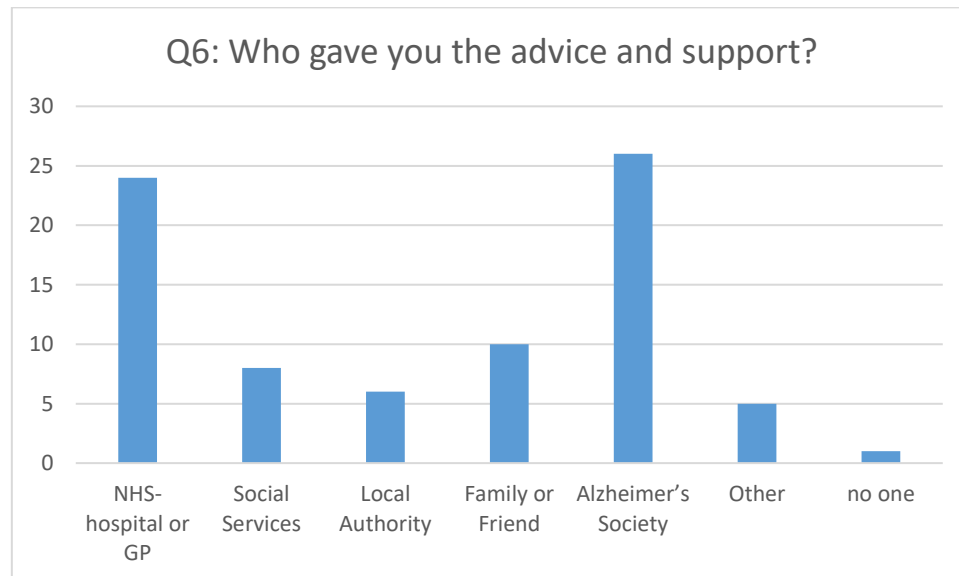
## 2.5 Did carers get the advice and support they needed?



Total=70

Getting relevant advice and support is important to ensure that patients and carers can make the right decisions and create care packages that work for all. Of those surveyed, 67% (47) felt that they did get the advice and support that they needed, with 26% (18) not receiving enough. Of 'other' responses, one reported that they sometimes had the right advice and support, and one felt the GP was the only source of advice and support.

## 2.6 Who gave carers the advice and support they needed?

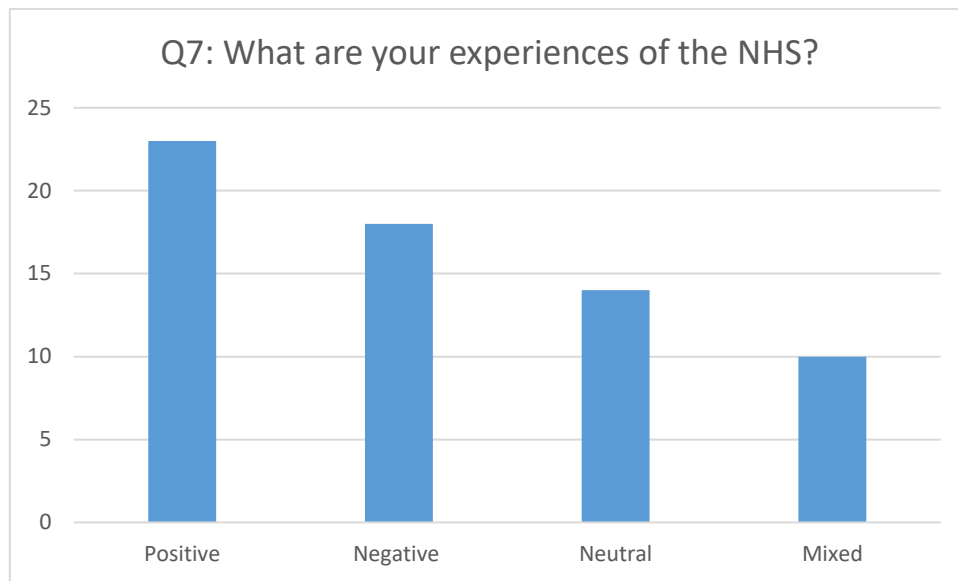


Total=80

When it came to providers of information, the NHS scored highly with 30% (24), although since 42% or 30 of those surveyed had been taken at Croydon University Hospital may contribute to this figure. That said, this reflects the quality. The Alzheimer's Society was highly regarded as providers of advice and information, even topping the NHS with 30% (24). Croydon Council advice services and Croydon Council Social services scored very low, whose duty it is to provide information, scored 10% (8) and 7% (6) respectively.

However, the Alzheimer's Society is commissioned by the CCG to provide information on dementia and provide a chance to talk to a Dementia Adviser at the Alzheimer's Society. Additionally, anyone with a diagnosis of dementia can be referred including self-referrals / GPs. This may reflect the high uptake of advice and support from Alzheimer's Society.

## 2.7 What were the carers' experiences of using the NHS?



Total= 64

Carers experiences of the NHS rated highest with 35% (23), but 28% (18) had a negative experience, 22% (14) was neutral and 15% (10) had a mixed experience. This question was very general of the whole NHS reflecting GP, hospital and community services, and so may reflect different services at different times, see the detail reflected below.

### Carers said generally:

“Very mixed, depends on who you get at the time, across the board.”

“The NHS services a have been mixed. Some have been first call an at other times I feel they failed my Mum’s best interests.”

“Overworked, long days- depends who you get.”

**Views of those carers using hospital services:**

“CUH - brilliant.”

“Very good.”

“Neurologist diagnosed my sister while looking for something else.”

“Well supported.”

“They work well and are helpful with my husband’s issues.”

“Some nurses not supportive or well trained, not understanding. Not treating underlying existing conditions. Relative had a brain scan but they are denying their condition.”

“Well supported. Were going to get discharged (on Queens) but I noticed medical issue, they questioned me (I’ve been caring for 2 years) but A&E listened and were brilliant.”

**Carers experiences about consistent support:**

“Slow, 7-8 months to get assessed, at memory service, from where mother was discharged when medication was seen to be ineffective and stopped, no continuity, no course on practicalities on how to deal with dementia suffer (from how to get her out of bath to faecal contamination).”



“ For dementia, so so, remember we are a medical family and pushed hard for my father’s care. One later hospital assessment week, in patient on phyc (psychiatric) ward was awful. My father, 78, had become too violent for my blind mother 68, to manage him alone over nights. He was in the wrong place for a week’s assessment even more violent in unfamiliar surroundings and hospitals stays were unknown to him. We were forced to agree to a quick medical quash. It took four weeks at home to get the Meds (medications) right for him. With SS (social security) fees for social care on the first PIP (personal independence payments) paid for social care, we <I alone> could then manage him at home.

“The GP was very concerned and helpful and also the Alzheimer’s dr (doctor) was very helpful. System is slack, M had a blood test - getting result was difficult, results suggested a new test, frustrating, I am in another country! Medication (caused her to be) zombied, lost so much weight, not eating, within a week of removal (of meds) back to normal. Brigstock medical, no call back, frustrating. called 111 as protein in urine, Mum couldn’t walk - all linked to blood test.”

“The doctor has been of help going on home visits. She has been under the MH team.”

“Very good, GP. Respectful, well looked after.”

“Been asking 18 months for diagnosis. Get referrals but no proper treatment. In and out of hospital not getting right care.”

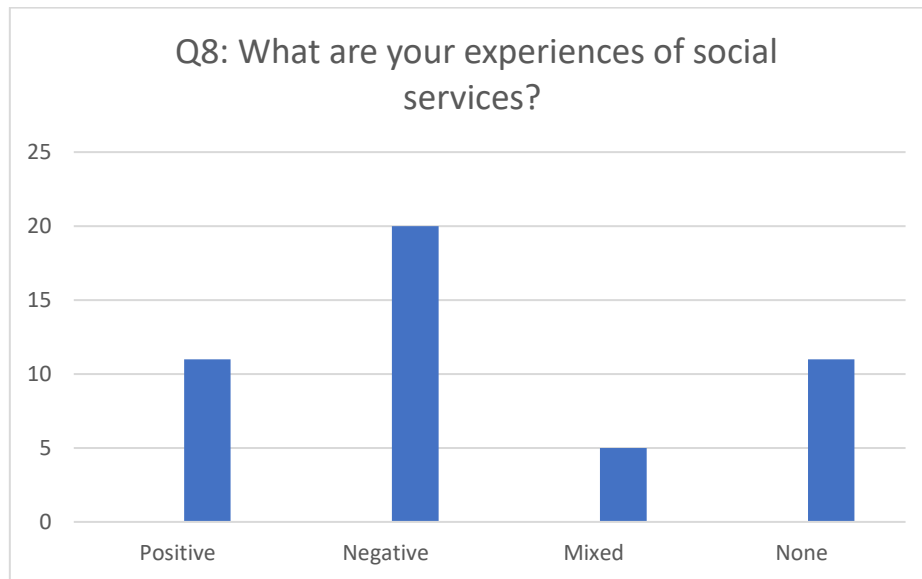
“NHS services not brilliant, GP not proactive at all regarding Alzheimer’s, Heavers (Alzheimer’s Society centre) however was very good.”

“Change GP, then got the right support eventually, I am named carer, should get a priority appointment, GP not aware of this. I’m having to tell them - I don’t want to have to be keep repeating myself about the same stuff.”

“The Heaver Centre prescribed donepezil for dad and I have a letter they sent him saying a joint care plan was in place with the GP, but there was never evidence of this.”

“GP slowing at taking my husband seriously. When my husband was saying to me he felt he had a problem with his memory for years.”

## 2.8 What was the carers' experiences of using social services?



Total=47

For carers, it is essential that they have an effective service which integrates the NHS services with council-run social services. For the carer and patient, the shift between one service provider and another should be smooth, to reduce unnecessary concern

Of those who did respond just 23% (11) had a positive experience and this was outweighed by the 42% (20), who had a negative experience. What is of interest is that 23% (11) had no contact with social services, suggesting either they were at an early stage of caring and did not need to call on social services, or did not want to disclose their involvement. A further 23 of those surveyed did not record a response, which suggests no involvement at all.

### Carers experiences of services, process and approach:

Some had a positive experience, even expecting that it was going to take a little time, others felt it took a long time to access information or support. There may be a link to understanding the process and then managing expectations of what could be done and when.

“I had to contact the local Social Services, very good, when I phone up they are excellent, but it does depend who you get, I had a social worker before who was not good.”

Social worker- difficult to say. Met once, first impression 'efficient'.”

“Social services have been very good according to my sister who deals with her wellbeing as lives nearer.”

“Slow but acceptable, have had carers assessment and assessment for diagnosed person brokerage have been very good to secure care staff.”

“Social services been ok. Reasonably responsive. Feel they have a big caseload, no continuity.”

“Social Worker was good but hard to get hold of. Leaving messages. Frustrating though when you need help.”

“Effective referral to day centre for my husband with dementia initially was able to book restbit (respite) and get it confirmed months in advance, that was not possible last year which was disappointing.”

“Trying to get my husband into a home, have been on a ward for two months.”

“Incredibly difficult to contact relevant department, very frustrating for carers.”

“Social Services are diabolical. Waiting three weeks so far for an assessment. We were told 7 days.”

“We have had a diagnosis for several years, had our first social services appointment next week.”

“Very difficult to contact, very slow to deal with anything, administration extremely poor, not at all what one needs as a carer for someone with Alzheimer’s adds to the already considerable stress - very disappointing.”

“Not helpful once the social worker found out that we were self paying we were turned down for CNC because I was looking after him too well.”

“They became involved later on but were not helpful.”

### Carers experiences of funding challenges:

The national funding policy is, of course, a constraint beyond that of Croydon Social Services, but it is this service that bears the frustration of those seeking financial support. Again, more clarity on the care process, ways and limits of accessing funding would help manage expectations.

“Relying on family, social services have offered us a day centre, 1 day a week, nothing else, £60 a day, a whole week’s money, Access memory clinic October 2014, diagnosis 2015, Social Services 1st appointment last Monday. Social services: 1st visit mention of money, she did say she hated doing it.”

“Selling house how much money we have. Social services need to be interested in mum’s welfare not costs so we haven’t bothered.”

“Non-existent. We are self funding as we are not eligible due to mothers savings.”

“Awful. No support/ feel alone. Pressure to cope with relative. What’s easier for them. Sell the house. Pressure.”

“Paying for out own care. Very expensive (£)100,000.”

“Huge social services appeals and tribunal etc. PIP for social care on top of all other fees, enabled me to give up my career teaching and retrained as care home manager/social worker L5, around my father and blind mother, and friends when visiting.”

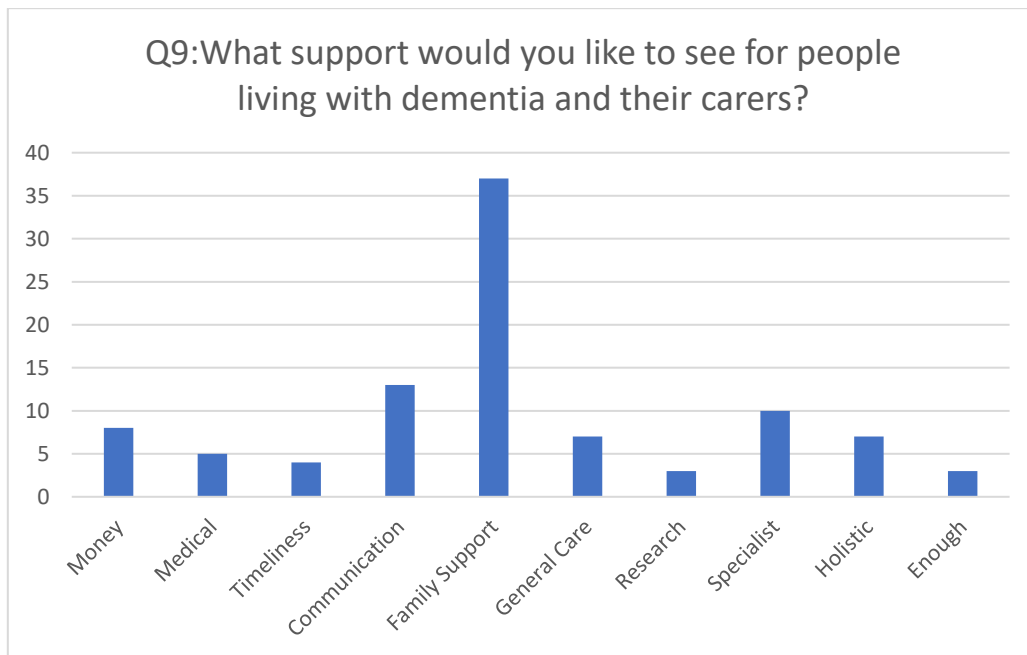
### Carers detailed experiences:

These are two full recorded experiences of managing through the system.

“Absolutely useless. When a social worker was first assigned to my mum she made loads of comments that she can do this and that for my mum, didn’t hear anything for a month, called and chased her, finally got her and had the same again, another month passed then received a call from her saying she was no longer the case worker, and that was the last we heard from them for over 2 years.”

“Because of his age, they said they wouldn’t consider providing the 6-week care package because the expense might serve no purpose as he could die within days/weeks. I had to be firm with them, refusing to take him home when he came to be discharged. Unfortunately, he fell, fractured his hip. Four weeks later and was operated upon at CUH. On discharge, social services declined to consider resuming the 6-week package and we have been paying for his care ourselves since. I am pleased to report that a year later he’s still very much alive and in his own home.”

## 2.8 What support would you like to see for people living with dementia and their carers?



Total=97

The graph above shows what Carers would like to see based on an analysis of their responses. We found the following themes

### Money

“I am paying for care myself at £600 a week.”

“Paying for everything.”

“Government to contribute in the same way as they do for NHS.”



“Carers allowance is a pittance, caring is a full time job, £62.70 for 35 hours

“I would like to appoint a care worker for a few hours a day but I can’t afford to pay, I understand I have to go online and fill a lengthy form and wait for assessment.”

**Medical responses were anywhere medicines and diagnosis were mentioned, such as:**

“Training for GPs and receptionist, I don’t want to hear excuses.”

“Care package, medications.”

“Regular check ups.”

**Timeliness refers to the speed of assessments and access to services:**

“I have been doing the night shift for five years.”

“Make it simpler when applying for help and respite care.”

Communication related to provision of general information, knowing where to go and who to speak to:

“Want all my options.”

“I need to know how to employ a (paid) carer’ ‘let them know what is available and for whom. It is sometimes a very difficult existence.”

Family support included emotional and respite care for families and carers of people living with Dementia. This reflected 38% of the total responses.

“Look at the whole family approach it is a full-time job to care.”

“more time for the Carer to go to the various events available by means of providing alternative care for the patients.’ ‘more stress relieving sessions, singing, dancing, yoga, lunch clubs.”

General care was in response to activities of daily living such as help with general care needs of the person who was being cared for:

“Someone to provide stimulation, Dementia walks.”

Research into Dementia:

“advice on research, plus any type of information on possible cures (doubtful).”

Specialist was where a social worker or specialist was requested such as access to a Specialist at every stage, as well as specific groups for younger people living with Dementia and Men’s groups:

“a visit now and then from somebody qualified in this area.’

Holistic was interpreted as treating the whole person, not the condition, and services working together to treat the whole person:

“The whole family approach.”

“Support in the form of specific advice about the person living with dementia and their carer.”

“More support than being treated as a number.”

“Working together, SS (Social Services), Alzheimer’s, forward planning and advice, what type of homes are available and recognise it is the condition, not the person.”

“I want carers to be listened to and not feel like they are wasting time.”

Three respondents felt that they had enough support:

‘(want to be left alone to) get on with it’,

‘All the support they required since finding the Carers Information Centre’,

‘We have all the support we need, thank you’

## 2.9 Further comments from questions 7 to 9 about experiences of services and what they would like to see.

### Support

There seemed to be a difference in comments between those who knew there was support and used it, and those who would like to use it if they could get their caring duties covered so they could attend support groups. A further group did not seem to have awareness or access to the kind of support services they needed to meet their specific circumstances. This may need a consideration of how support services are delivered and prioritised across a network of providers.

“There is plenty of good support already, just visit the carers centre.”

“I would like to appoint a carer or carers at least a few hours a day but I can't afford to pay I understand I have to go online and fill a lengthy form and wait for assessment it maybe takes a long time “

“Need more support some days I am on my own carers café good, family are busy/ far. Work and family. Need groups.”

“Support needs to be met for the carers, and support for the individual. Medical check ups need to be more regular.”

“I could have done with support for me, respite. Fortunately friends helped.”

“ (I) want all my options, GP to take me seriously, CUH to diagnose us, going to be discharged without tests. Getting worse not better.

“More practical courses (not just handouts / fact sheets) at locations and times of day that don’t clash with school run. More stress relieving sessions (singing/ dancing /yoga/ etc) my lunch clubs. More carers allowance as caring is usually a full time job, £62.70 for 35h is a pittance.”

“More home visits from specialists to support the carer, support in the form of specific advice about the person with dementia and emotional support for the carer.”

“Time to take more time for carer to go to the various events available by means of providing alternative care for the patient.”

“I would like to appoint a carer or carers at least a few hours a day but I can’t afford to pay I understand I have to go online and fill a lengthy form and wait for assessment it maybe takes a long time.”

“Power of attorney...Age UK provided information on a donation basis, why isn’t this information publicly/easily available?”

## Service provision

Continuity and closer relationship between providers and clients are considered important to maintain. There is also a sense that some services are doing a good job such as the memory service but they need to be better financed. Conversely care homes need to be more affordable for carers and families.

“Names (named) SW (social worker) continuity throughout someone provide stimulation, befriending type, social interaction go out walking.”

“The memory service could have supported us better and been more flexible about visiting us at home, despite knowing how difficult I found it to get to their premises.”

“Closer relationship to GP, same GP 47 years, relationship, confidence/trust/contact not just a number.”

“I would like carers to be listened to and not feel like they are wasting time.”

“More day centres and more places like forget me not café, cheaper care homes.”

“Make it simpler when applying for help and respite care.”

“There is nothing my husband can attend for his age group. Day centres seem to be for people in their late seventies/eighties. The government have got to look at people getting early onset Alzheimer’s .They never mention the ones in there sixties or younger .They need to wake up .And get there heads out of the sand.”

## Process

“Nightmare time getting the 25 per cent discount on the council tax. Too many forms to fill in one for the attendance allowance one for the carers allowance, which you can't apply for until you know about the attendance allowance. Council tax rebate was ridiculous had to get a certificate from the GP. The fact that we were already claiming the attendance allowance wasn't relevant. Took months before Croydon Council finally agreed to give the discount. More needs to be done offering a basic respite care system for the carer. Just being able to phone a number and ask for someone to come and sit with the person for 2-3 hours would help. Friends and neighbours make promises they will help the reality is most carers are on their own. Or a neighbour will do it once realise what is involved and then never offer to help again. Not pleasant for the carer who is left feeling embarrassed.

“Advice on research plus any type of info on possible cures (doubtful) much more accessible information and help for carers also more respite needed.”

“A one stop shop at the point of diagnoses where all necessary info and directions of how to access help is available.”

“To get help and advice at an early stage and put in contact with the right bodies that can offer help.”

“Power of attorney this info isn't out there, it needs to be out their early.”



## Respite

Respite care is important to give carers a break and also time to gain more information and support. If it not available for moderate care, this should be considered. If it is available then it needs to be promoted better.

“Respite opportunities, more readily available when the condition is maybe only moderate.”

“More centres to attend to give carers respite. Have had good care by private. Very draining.”

“More day care and respite. I am stuck at home every day except Friday when my husband goes to day care for which I have to pay £40. Cannot go to see friends or support groups as he will wander or do something dangerous in the house.”

## Integration

It clear that a more integrated service between providers would make a real difference, particularly in the switch between NHS and social care.

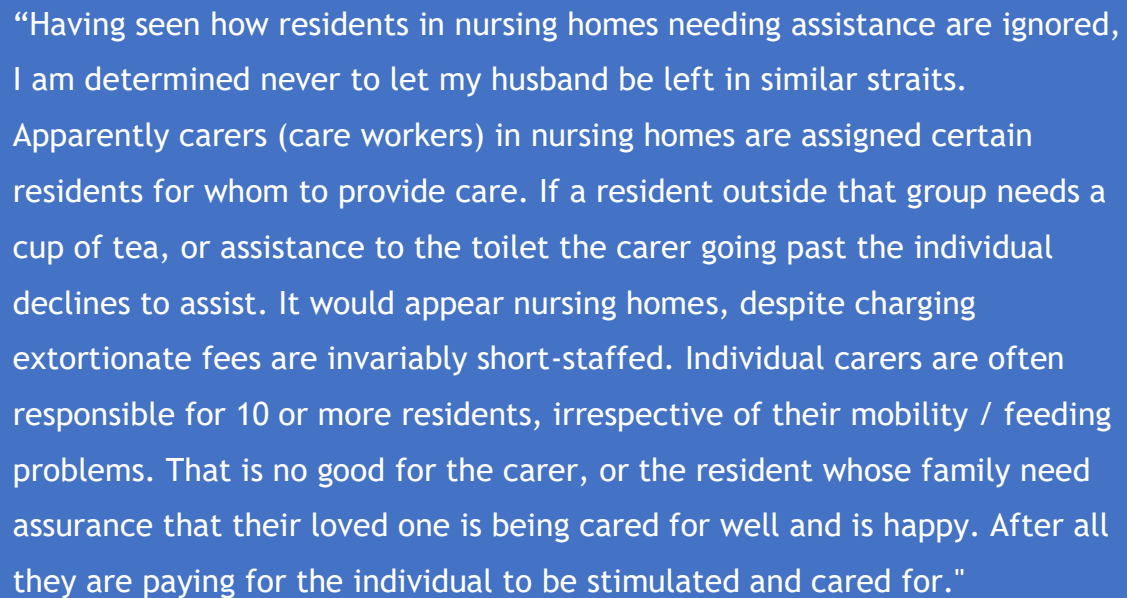
“More joined-up services, more clear sign posting, easier access and information, more empathy and clarity.”

“I'd like unified approach NHS. Social services falls down there.”

“Training for GP and receptionists, I don't want to hear excuses, my one priority is continuity of care for my husband, if you can't help me tell me, be dealt with on a case by case basis, why should we be put in a box. Care home issue needs addressing, none run by council, all private/ money making.”

## Quality

There is a concern that some nursing and care homes do not meet the quality expected.



“Having seen how residents in nursing homes needing assistance are ignored, I am determined never to let my husband be left in similar straits. Apparently carers (care workers) in nursing homes are assigned certain residents for whom to provide care. If a resident outside that group needs a cup of tea, or assistance to the toilet the carer going past the individual declines to assist. It would appear nursing homes, despite charging extortionate fees are invariably short-staffed. Individual carers are often responsible for 10 or more residents, irrespective of their mobility / feeding problems. That is no good for the carer, or the resident whose family need assurance that their loved one is being cared for well and is happy. After all they are paying for the individual to be stimulated and cared for.”

# 3 Findings & Recommendations

## 3.1 Findings

Based on what we have heard these are our findings:

**GPs are crucial to the experience:** GPs have a critical role in being a gateway to services, so confidence in them diagnosing early and referring patients and carers effectively needs to be good. Nearly 1 in 6 did not feel they had had this experience in Croydon.

**There is confusion about pathways for support:** Having an understanding of a clear pathway for support is significant in helping patients and carers cope with their situation. Many patients in Croydon were confused about how they accessed the right sources of information and support.

**Right support at the right time:** Getting the appropriate support at the right time is also crucial to the experience that carers and patients experience. A third of those surveyed in Croydon felt they did not get what they needed, when they needed it.

**NHS service experience is mostly positive, but good practice needs to be shared:** The experience of using NHS services was mostly positive, but there can be a variety of experiences of different parts of the service from GPs to hospital care. Sharing best practice on how to support carers of those with dementia, would help bring a more consistent service experience for carers and cared for.

**Social care advice and support seems to focus on finances first before care options:** While some found social services supported them, many service users stated that there was a lack of useful information or help. There seemed to be too much emphasis on financial aspects of providing care and process issues, instead of focusing on the caring and support needs that carers and patient need. While we understand the significant issues in both personal finance and resources, much of this is linked to the need for effective information and communication.

## 3.2 Recommendations

**These are our recommendations linked to provider and commissioner:**

Based on our findings we make the following recommendations for the Croydon Dementia Action Alliance (CDAA), Croydon Clinical Commissioning Group (CCG), GP Collaborative (GPC), Croydon Health Services (CHS), South London and Maudsley NHS Foundation Trust (SLAM), Croydon Council Social Services (CCSS) and voluntary organisations such as Age UK and Alzheimer's Society.

**Ensure all GPs are fully compliant with national guidelines in diagnosis and response times for referrals. (For CCG,GPC):** Since GPs are the gateway to services it is important that they all are providing the same quality of service irrespective of provider. Surgeries providing best practice could share their knowledge and experience across the network to ensure consistency.

**Ensure suitable and easy to access signposting for support is available from GP and community level. (For CCG, GPC, CHS):** One of the challenges for carers is in finding suitable and easy to access signposting from the GP. Croydon has both the Carer Information Service and specialist support from Alzheimer's Society and Age UK, it just needs to link together for clearly when GPs refer patients for diagnosis and support services and be there for all access points on their journey.

**Present the appropriate pathways of support and information in clear way which can be easily understood by carers, perhaps as a leaflet and online material. (For All):** For carers, clarity on the journey they must take would help their experiences significantly. While it is a complex process of different providers and options, a simple and easy to understand guide to the journey, available across all providers would help manage expectations and support effective decision-making.

**Each NHS service to review their service delivery where patients with dementia are involved to ensure they meet patient and carer needs at each stage in the customer journey (For CHS, SLAM, CCG):** Patients with dementia and their carers, need the NHS to provide a service that meets their specific needs. Becoming

Dementia Friends as well as training staff and reviewing processes will help ensure their needs are met.

**Review social service information and support to focus on care options before considering finances and explore further service experience by carers. (For CCG and CCSS with the involvement of the CDAA):** While we understand the limits that social services can do in respect for carers based on their financial situation, this does not hinder delivering effective advice and information needs to focus on care and support separate to the discussion on with financial aspects. When you usually buy a service, you would expect to see some of the range of options before the seller asks you how much you have. This is not that different for social services. By presenting all the options, showing the difference between those on different funding streams, carers can see all the relevant pathways and then effectively decide based on their financial situation. We understand that a number of changes are taking place so suggest that the experience of carers using social services be further explored at a later date.

**Continued monitoring of patient and carer experience by all service providers to see how service experience has changed in previous 12 months. (CHS, GPs, CCDA and Healthwatch Croydon):** This insight report has presented carer experiences, but should be seen as a beginning rather than an end. By continuing monitoring patient and carer responses going forward we can measure how changes in services have impacted patient experience and help resolve issues when they occur rather than months or years later.

**Apply the power of the One Croydon Alliance (All):** The opportunity of the OCA to bring all key parties together to find solutions, as they are doing in so many health and social care areas, could also be applied to meeting the needs of dementia patients and their carers and make a more integrated service.

## 4 Responses to our research

Before publication, we shared this report and its full data with the relevant providers and commissioners of services to give a response to our recommendations and findings. This is their responses:

### Rachel Carse, Dementia Action Alliance lead & Social Inclusion Coordinator, Croydon Council

Listening to the views of carers and people living with dementia is something that the Croydon Dementia Action Alliance (CDAA) takes very seriously. We would like to thank Healthwatch for this report and we appreciate the contributions from the carers and family members who have shared their views.

In the past year, the membership of the CDAA has grown substantially due to Croydon Council funding a full-time post to increase its reach and impact.

All organisations mentioned in this report are members of the CDAA. We are already working collectively and individually to make improvements for people living with dementia and their carers.

Every Practice Manager in the borough has recently attended a 'Making your GP practice Dementia Friendly' session. The Council, Clinical Commissioning Group, Croydon Health Services and South London and Maudsley NHS Foundation Trust are working together to make the journey seamless from diagnosis to support with health and social care needs.

CDAA will continue building on the extensive work achieved so far locally this year including the improvements highlighted in the report.

- **Funding of advice and support services structure:** Both the council and CCG fund dementia services across the borough. The Council has excellent day services supporting people living with dementia and their carers. The CCG provides the Memory Assessment Service, which formally diagnoses if someone has dementia. After diagnosis, the Alzheimer's Society, also

funded by the CCG, provides everyone with information on dementia and offers the chance for people to talk to a Dementia Adviser. Importantly, anyone with a diagnosis of dementia can be referred to the Alzheimer's Society including self-referrals or referral from a GP.

- **Information on how residents contact adult social care and its services:** Following in-depth analysis of the way residents contact the council, it became apparent that a different approach was needed for this to work better. From March 2019, the Council is moving to a model where there is greater provision of information, advice and guidance and earlier intervention to prevent, reduce or delay peoples need to receive social care. It will be a multi-agency, multi-disciplinary approach, working together with the safeguarding team, mental health service, Croydon police, the FJC anti-domestic abuse service and communities in the borough.
- **Clearly presented pathways:** The path of a person living with dementia and how they and their family negotiate services can be extremely complex and that is borne out by the comments in the report. The Council and other stakeholders are starting to work on how to create clear information about dementia, identifying what is available around the borough in a bid to make things easier to understand.



## Croydon Clinical Commissioning Group

NHS Croydon CCG welcomes Healthwatch's report and their interest in this important area that affects so many of our residents. Alongside our partners in the Croydon Dementia Action Alliance, we are working hard to make improvements for people living with dementia, their carers and families. This report will help us further focus our efforts for local people. In particular our current work during 2019/20 includes:

- Introduction of a new, national diagnosis dementia assessment framework - the CCG and Dementia Service providers are expected to adopt a more nuanced approach to diagnosis taking into account age and gender differences. This will lead to improved diagnosis rates, earlier detection and treatment, and better outcomes. The CCG will work alongside GPs and Primary Care to ensure implementation of the framework.
- Information for patients and carers - the CCG will ensure that leaflets and posters are available for patients and carers in all GP surgeries. Primary Care information systems alert GPs to relevant referral forms on the dementia pathway. The CCG will review the possibility of introducing IT carer assessment alerts to ensure comprehensive cover and onward referral to local voluntary bodies.
- Carers Registers, including dementia carers - GP surgeries maintain these registers which alert GPs and primary care health workers about an individual's carer status. Surgeries can then provide help with the carer's own physical, mental and emotional health plus signposting to support groups. Multidisciplinary "Huddles", including Dementia Huddles, are meetings of relevant professionals involved in delivering health and social care. They are being embedded in all General Practices across Croydon, and will have a positive impact on timely access to services.
- Dementia Pathway - the CCG is facilitating a workshop in February 2019 with local stakeholders including the South London and Maudsley NHS Foundation Trust, GPs and voluntary bodies. The outcomes of the CCG facilitated



Dementia Pathway Workshop will inform the ongoing work of the One Croydon Alliance.

- The Healthwatch report findings and recommendations will inform the workshop agenda. The need to develop information about the various services delivered in the pathway that is user friendly could be one of the outcomes of the meeting. The CCG will work with partners and communication professionals to develop user-friendly promotional material.
- The new NICE Dementia guidelines include provisions for care co-ordination and care planning and psycho-education for carers. This will give them skills and strategies for dealing with the challenges of caring for people with dementia. The CCG will work with our partners to make sure that these new standards become part of dementia pathway ways of working.
- The CCG will continue its 'Dementia Friendly' staff training programme.
- The CCG will monitor all the health services we commission for dementia, including the local mental health trust and the Alzheimer Society, to make sure that quality standards are continuously improved including services that directly impact on carer experience.

## Croydon Health Services NHS Trust

We welcome this report by Healthwatch Croydon looking at the experience of carers of people with dementia in our borough. With our ageing population, rates of dementia are rising and more people are finding themselves caring for their loved ones.

There are a number of measures we already have in place for patients with dementia including:

- Annual participation in the National Audit of Dementia which benchmarks us against other trusts and suggests actions for improvement.
- Identifying people with cognitive impairment or delirium and signposting them to their GP for further follow up care and support.
- Telephone contact with all carers of any patients with delirium to assess people's experiences of our care.
- Ongoing monitoring of our services through the Friends and Family Test and our PALS team.
- Participation in the Croydon Dementia Action Alliance and more than 370 staff trained as dementia friends.
- Support for John's Campaign, to ensure flexible visiting hours for carers on our wards, and the Herbert Protocol to protect vulnerable people in the community.

However, we know there is more than can be done to ensure services are fully joined up between health and social care. We will study the recommendations closely to look at whether there is more we should be doing to support carers of those living with dementia. We will also work closely with our partners across health and social care to see what additional actions are needed to create truly integrated services.

### South London and the Maudsley NHS Foundation Trust

The report will be used to inform discussions we will be having with our Service User and Careers Action Group (SUCAG), to ensure we continue providing high standards of care, including a new care pathway for people with dementia in Croydon.

### Carer's Support Centre

We're pleased to see Healthwatch Croydon highlighting issues faced by carers of someone with dementia in Croydon. It is positive to note examples of good practice, including carers using the Carers Support Centre for information and advice.

However, it is concerning that many carers are not being identified early enough and signposted to the help they need. Our 2017 *Not Just a Patient* report found that 82% of carers had not been informed by their GP of carer support available in the community.

There is clearly still work to be done to ensure every carer of someone with dementia has clear pathway to appropriate support and advice. We invite Croydon Council and Croydon CCG to liaise with us on this issue, to ensure all carers are aware of the services we offer.

# 5 Quality assurance

## Design

### Does the research ask questions that:


**Are pertinent?** This research asks carers of those with dementia in Croydon their experiences of obtaining a diagnosis for the person they care for, and their experience of services. As one of largest boroughs of over 65s in London and with 3250 people registered as diagnosed with dementia, and a prediction of an increase in the coming years, this research is very pertinent.

**Increase knowledge about health and social care service delivery?** This research helps both commissioners and providers of services both in the health and social care sectors. Real experiences of carers using the services now, will help inform knowledge for the future delivery of services.

### Is the research design appropriate for the question being asked?

**a) Proportionate:** We know there are around 2339 diagnosed with dementia and over 3000 project it to have the condition but are undiagnosed. It would suggest that there may be a similar number of carers, but we do not know for sure, since numbers are counted on those who register for services. In seeking to ask for view from a group that is seldom-heard and hard-to-reach, and in some cases may not access services, or only use them as a last resort. The 70 carers we have heard from is proportionate number from those we have access to via our network of community organisations and the health services.

**b) Appropriate sample size:** Has any potential bias been addressed? We have spoken to carers while in hospital with their cared for in elderly wards, as well as those accessing service via Alzheimer's Society in Croydon and the Carers Information Service, as well as promoting an online survey for those who may not be able to access services directly. We extended the time for the survey to gain



experiences from a three month to six-month window so we could access more experiences. We accept the limits of this research, but state any bias has been addressed. We refer to the fact that 25% (18/70) came from elderly wards in the hospital and so may have leant heavily to experiences within the NHS and particularly hospitals.

**Have ethical considerations been assessed and addressed appropriately?** Carers were always given the opportunity to refuse our request for their views. We understand the pressure and concerns they had and worked closely with relevant organisations such as Croydon University Hospital, Alzheimer’s Society and Carers Information Service.

**Has risk been assessed where relevant and does it include?**

- a) **Risk to well-being:** None.
- b) **Reputational risk:** That the data published is incorrect and not of a high-quality standard. Careful checking and referring to relevant organisations has been undertaken before publication.
- c) **Legal risk:** Have appropriate resources been accessed and used to conduct the research? There was no need to refer to legal resources for this research.

**Where relevant have all contractual and funding arrangements been adhered to?** This did not relate to any specific contractual or funding arrangement. It was referred to by the draft business plan agreed with the commissioner.

**Data Collection and Retention**

**Is the collection, analysis and management of data clearly articulated within the research design?** Yes.

**Has good practice guidance been followed?** Yes.

**Has data retention and security been addressed appropriately?** Yes.

**Have the GDPR and FOIA been considered and requirements met?** Yes.

**Have all relevant legal requirements been adhered to ensure that the well-being of participants has been accounted for? ie the Mental Capacity Act.** None required for this research.

**Has appropriate care and consideration been given to the dignity, rights and safety of participants?** Yes, particularly on hospital wards and with support groups where we worked closely with relevant staff

**Were participants clearly informed of how their information would be used and assurances made regarding confidentiality/anonymity?** Yes.

### Collaborative Working

**Where work is being undertaken in collaboration with other organisations have protocols and policies been clearly understood and agreed, including the development of a clear contractual agreement prior to commencement?** There was not contractual agreement for this research, but our working with partners was clearly agreed in advance of research taking place. The Croydon Dementia Action Alliance gave advice in the drafting of the questions.

**Have any potential issues or risks that could arise been mitigated? These are shown below:**

Risk factors	Level of risk	Contingency
Cannot access key people to research	low	Going on to hospital ward / captive audience
Organisations let you down	medium	Use social media
Question set does not work with group	low	Co-written by CW at frontline of service delivery
Data is seen as being out of date	low	See above
Not enough respondents	medium	Extend survey time

**Has Healthwatch independence been maintained?** Yes, this research is shared with partner organisations before publication for their comment, but only factual inaccuracy would be reviewed. This does not affect the comments of experiences we receive.

## Quality Controls

**Has a quality assurance process been incorporated into the design?** There was a proper process of scoping.

**Has quality assurance occurred prior to publication?** Data collection was checked and re-checked.

**Has peer review been undertaken?** No peer review was undertaken. It was not required for this research project.

## Conflicts of Interest

**Have any conflicts of interest been accounted for?** The Croydon Dementia Action Alliance gave advice in designing the questions. We mention their role in the recommendations since they have a key role to play in influencing change in services. This research does not state a view on the work we do. Likewise, the Alzheimer's Society and Carers Information Centre, helped us promote the survey and gain access to carers, but their own work is not the focus of this study. References to their services have come directly from the carers.

**Does the research consider intellectual property rights, authorship and acknowledgements as per organisational requirements?** The research is owned by Healthwatch Croydon, who are managed by Help and Care. Other organisations support has been recognised and suitably referenced.

**Is the research accessible to the general public?** It appears on our website as of 11 February 2019

**Are the research findings clearly articulated and accurate?** To the best of our knowledge, we believe they are.





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<http://www.poppi.org.uk/>



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