



Healthwatch Lambeth
Review of Dementia Services
in Clapham Park SW4



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**Healthwatch Lambeth
is the independent
health and social care
champion for local
people.**

About Healthwatch Lambeth

Healthwatch Lambeth is the independent health and social care champion for local people. We work to ensure your voice counts when it comes to shaping and improving services. We address inequalities in health and care, to help ensure everyone gets the services they need. We are a charity and membership body for Lambeth residents and voluntary organisations.

There are local Healthwatch across the country as well as a national body, Healthwatch England.



Executive Summary

Healthwatch Lambeth undertook a review of dementia services in the Clapham Park area of Lambeth during the second half of 2014. With the number of people with dementia set to double in the UK over the next 30 years, we were keen to:

- Gain an insight into the experiences of local residents with dementia and their carers (both paid and unpaid)
- Explore how well different local health and care services worked together to support people with dementia, their families and carers.

Our review combined Enter and View visits to two care homes and two extra care schemes, discussions with carers and interviews with a range of local health and care providers for people with dementia.

Our overall impression from our Enter and View visits is of residential services that provide good basic care but are not always able to work in ways to enhance the lives of the people they care for, particularly in terms of collaboration between different on-site providers to deliver joined up person-centred services and supporting social interaction amongst residents. While the facilities were safe and accessible, we found limited evidence of friendships, activities or opportunities for residents to make personal choices.

And while connections with other local health and care services were generally good, the facilities and their residents seemed largely isolated from the neighbouring community.

Our exploration of other dementia services in the area revealed a lack of coordination and ambition to drive forward integrated dementia care. Low referral rates to the Memory Service and limited use of dementia advisor support were mirrored by a noticeable lack of collaboration and sharing of knowledge across the dementia programmes run by Southwark and Lambeth Integrated Care (SLIC) and the Health Innovation Network (HIN). Family carers meanwhile had mixed experiences of services and wanted to see more automated referrals for social services assessments and consistency of services and support groups.

Given social isolation is likely to contribute to higher levels of dementia amongst our growing older population, we are concerned that residential schemes for this age group do not seem to be commissioned, designed or delivered to address the risk of loneliness. Our first set of recommendations challenge commissioners and contractors to tackle this issue by fostering more joint working amongst providers; building meaningful social interaction opportunities for service users into contracts; exploring volunteer visiting programmes; and valuing the role of care staff in building meaningful relationships with residents.

Our second recommendation is for the establishment of a Dementia Action Alliance for Lambeth to champion dementia services and build a coordinated response from Lambeth citizens, service providers and commissioners.

Healthwatch Lambeth is ready to play its part by completing Enter and View visits to all the borough's extra care schemes; gathering views of other people with dementia using domiciliary care; and documenting people's experiences after discharge from the Memory Service.



Introduction

Healthwatch Lambeth undertook a review of dementia services in the Clapham Park area of Lambeth during the second half of 2014.

This report provides a brief overview of the project, sets out our findings and identifies further action for both Healthwatch Lambeth and our partners, including commissioners and providers of services and support for people with dementia.

Review Scope

Why dementia services?

We chose to review community-based services for people living with dementia in response to:

- The rising numbers of people living with dementia in Lambeth and raised awareness of their needs as highlighted nationally by the work of the Alzheimer's Society and the government's dementia strategy and Prime Minister's dementia challenge 2020
- Growing emphasis on developing integrated health and social care provision
- Community concerns about the quality and safety of care homes and extra care¹ housing schemes for older people, and Lambeth Council's interest in increasing extra care provision (which isn't inspected by the Care Quality Commission (CQC)).

There are approx 13,000 people in South London diagnosed with dementia, with a further estimated 15,000 who are undiagnosed. The prevalence of dementia is expected to increase by 13% by 2020.

Dementia Factsheet Health Innovation Network

Our objectives

We were interested to explore and understand what works and what doesn't within different care settings for people with dementia. Our review looked to:

- Gain an insight into the experiences of local residents with dementia and their carers (paid and unpaid)
- Explore how well different services such as health and social care, community and other local services worked together to support people with dementia, their families and carers.

We devised an ambitious person-centred approach to the review, combining Enter and View visits to care homes and extra care schemes, and interviews with a range of service providers.

Why Clapham Park?

The Clapham Park area (SW4) was identified as a useful location to focus on, as there are a number of care homes, extra care housing schemes and a day centre in the area, together with primary care and social care services.

¹ The term 'extra care' housing is used here to describe developments that comprise self-contained homes with design features and on-site domiciliary care and support services available to enable self-care and independent living. <http://www.housinglin.org.uk/Topics/browse/HousingExtraCare/>



Methodology

The review was carried out between April and November 2014. We gathered information and experiences from a range of stakeholders using the following methods:

- Enter and View visits to four residential care facilities housing 170 residents in total:
 - Two care homes: Alver Bank and Collingwood Court
 - Two extra care schemes: 44 Clarence Avenue and Charleston House
- Surveys of residents' family members and the care facilities' staff
- Meetings with each of the service managers
- Interviews with other service providers: four General Practitioner (GP) surgeries, Southwark and Lambeth Integrated Care Programme, Health Innovation Network's Dementia Programme, Lambeth and Southwark Memory Service, Healthy Living Club, Alzheimer's Society Lambeth and Southwark, four local churches and two Lambeth Council commissioners with responsibility for older adults
- A meeting with family carers at the Healthy Living Club
- An informal visit to Stockwell Day Centre (located at 44 Clarence Avenue)
- A public workshop to explore our findings.

In total we heard from 45 residents, 26 family members (although none with relatives at Charleston House),² 18 care staff³ and four managers through our Enter and View visits, four family carers at the Healthy Living Club and 13 representatives from other service providers and community organisations.

Limitations

All the residential facilities we visited housed people both with and without dementia. Three of the facilities reported that two thirds of residents had the condition: Clarence Avenue reported none but this was not borne out by our visitors' observations. Where we spoke to residents with dementia, feedback was understandably limited. In addition to our own observations, we therefore drew insight mostly from the views of other residents on the quality of the home or scheme, and other local health and care services they used.

Our discussions with family carers and advocate bodies such as the Alzheimer's Society supplemented our insights into the experiences of other people living with dementia in the local area.

About Enter and View

Healthwatch has a duty to 'Enter and View' publicly funded adult health and social care services. This enables us to observe service delivery and to gather people's views and experiences as they receive care. But we are not inspectors like the Care Quality Commission (CQC). All our Enter and View visitors are trained and feedback is anonymised.

Our Enter and View reports of the four facilities we visited during the review are available on our website: www.healthwatchlambeth.org.uk/enterandview

² Family survey respondents: Alver Bank: 9, Collingwood Court: 11, Clarence Avenue: 6.

³ Care staff survey respondents: Alver Bank: 5, Collingwood Court: 10, Charleston House: 1, Clarence Avenue: 2.



Findings and Analysis

Our findings are presented in two parts:

- Section A focuses on our Enter and View visits
- Section B considers other community services for people with dementia in the SW4 area.

Section A: Enter and View visits

The Enter and View team used elements of the patient-led assessments of the care environment (PLACE) criteria for hospitals⁴ and Alzheimer's Society's guide to choosing a care home⁵ to assess the facilities we visited. The table overleaf provides an overview of our observations of each facility and below, we present the over-arching findings from the four separate reports.

Overall, we felt that across the four care facilities standards were generally good and the facilities were safe and accessible, with other local services in the area on the whole meeting the residents' needs. Alver Bank had met the CQC standards in its most recent inspections; Collingwood Court had not met three of the required standards as at September 2014.⁶

Physical environment

The physical environment in all four facilities was largely good. However, in each care setting there was scope to enhance facilities to improve the residents' quality of life - particularly to promote more meaningful interaction and purposeful activity between residents, their families and staff. Some specific points are featured below.

Exteriors

Three of the facilities had outdoor facilities for residents to use. Alver Bank did not have suitable grounds but the manager was making plans for the garden to be made safe and accessible. However, the home has been operating for many years without providing appropriate outside space for residents. The garden area at Clarence Avenue was accessible and safe but there was no outdoor seating or shaded area for tenants to use comfortably. Following our visit, all four facilities were looking at improving the external spaces so that they were both safer and more welcoming for residents to use.

⁴ PLACE visits <http://www.england.nhs.uk/ourwork/qual-clin-lead/place/>

⁵ Your handy guide to selecting a care home (PDF) http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=1003

⁶ The unmet CQC standards at Collingwood Court: Treating people with respect and involving them in their care; Providing care, treatment and support that meets people's needs; Quality and suitability of management: <http://www.cqc.org.uk/location/1-127810498/inspection-report/INS1-1375398734>

Table 1: Summary findings from our four Enter and View reports

	44 Clarence Avenue extra care scheme Provider: Sanctuary Care	Charleston House extra care scheme Provider: Allied Healthcare	Alver Bank care home Provider: Salvation Army	Collingwood Court nursing home Provider: BUPA
Physical environment - exterior	Pleasant and well-sized but no outdoor seating in the garden	Limited area but accessible garden space	Pleasant frontage with plans to develop an accessible garden at the back	Limited outside area - uneven paving and planting needed attention
Physical environment - interior	Good - pleasant but communal spaces under-used	Good - some access/height issues for wheelchair users to be addressed	Good - facilities partly confined by limitations of period building	Fair - institutional rather than homely, with small, slightly shabby communal areas
Safety and security	Good	Good	Good	Good
Dementia friendly environment	Good - contrasting surfaces though not block colour; bedroom doors not personalised	Fair - not all surfaces contrast	Fair - bedroom doors not personalised and not all surfaces contrast	Fair - personalised bedroom doors but lack of contrasts for different surfaces
Communal eating facilities	Service available on weekdays, inconclusive visit findings	Residents unhappy with recent contract change due to cost, choice and portion size	Good - menus with choice on display	Good - menus on display (although apparently out of date) and drinks and snacks available
Quality of care	Time pressures and staff rotation negatively impact the strength of relationships and service received by some residents	Fair- staff well liked but variable response times to emergency pull cords a concern to residents	Good - staff liked by residents and families happy with the service provided	Good - staff seen to interact well with residents and relatives satisfied
Friendships and activities	Isolated residents - situation exacerbated by remote location and limited activities programme with low participation levels; no trips	Friendships evident but residents report limited activities, especially at weekends, and desire for more input into scheme	Good rapport between residents rather than friendships. One activity coordinator - mixed views; no trips	Few friendships or visitors evident. Two activity coordinators but no trips
Service integration	Limited - apparent lack of coordination between scheme, landlord and council-run activities programme; good access to health services	Health service accessible by residents, though no GP visits to the scheme; good coordination between scheme and landlord	Good - Manager and staff content with other health and care services - some relatives less happy with GP approach	Good - Regular visits from local GPs but could benefit from better communication to progress non-urgent treatments



Interiors

Overall, we found the interior environments to be well maintained and pleasant for residents, with the exception of Collingwood Court where we felt the lounge to be small for the numbers using them and in need of refreshing. Both care homes were already looking at some new furnishings and decoration to brighten and update the environment.

The communal areas at Clarence Avenue, although in good condition, were remote from the circulation areas. We found residents sitting in the front hallway rather than the communal sitting and dining rooms, in order to feel part of the coming and goings of the building. This was not an appropriate space as there was no proper seating and much of the area was taken up by a large unused serving counter for food that the landlord said it is planning to remove.

Dementia friendly environment

None of the four facilities had been designed in line with current best practice for people with dementia. Whilst redesigning a whole scheme would be unrealistic, there is scope for looking at improvements to make residents' lives easier. For example, in each of our Enter and View reports, we have recommended simple steps that could be made to assist residents to identify their own rooms or front doors and communal bathrooms, and to ensure contrasts between surfaces in future redecoration programmes.

Quality of care

During our visits we witnessed generally kind and appropriate care of residents by staff across all four schemes. While feedback from residents was limited because most were living with dementia, most seemed content. Residents said *"I am happy and living here is important"*, *"[The staff are] brilliant"* and *"I belong to places like this, I spend quite a bit of time here"*.

All 19 families who responded to the question 'How do you feel about the personal care your relative receives?' were positive about the service provided by the care facility. Nearly half of these families identified their relative as living with dementia. Remarks included: *"My mother always seems happy, well fed and clean"* and *"I am unable to visit regularly but when I do, I am happy with the care my aunt receives considering she can be quite difficult at times regarding her personal hygiene"*.

Feedback from staff suggested a more varied picture. Seven of the eight positive responses from staff (all at Collingwood Court) indicated that they felt the service provided to residents was good and would recommend it. Those that would not recommend the care facility they worked at cited a variety of reasons including dissatisfaction with management, lack of resources (both equipment and personnel) to fulfil their roles, and low pay.

Resourcing

Our visitors did identify various resourcing issues through their own observations and discussions with residents, particularly regarding the amount of time care staff were able to spend with residents. One relative of a Collingwood Court resident noted: *"Resources seem stretched"*.



Review of Dementia Services

Our overall impression is of services that provide good basic care but are not always able to work in ways to enhance the lives of the people they care for. We saw staff who were committed and caring, but often frustrated at the limits of their role. Several told us in their survey responses that they did not have time to chat to residents or get to know them, which should be a key part of their role in providing care and support.

A staff member from Clarence Avenue pointed out that logistical arrangements around staff rotas also did not help to support relationship building: *“There are six different work patterns which we could be allocated to. This means that we do not get to see the same tenant every day so it works against getting to know them.”* This is particularly pertinent for residents who do not have visitors and who are less able to mix with other residents, as the care staff are their only ongoing contacts and relationships.

A number of staff survey responses advocated for service providers to employ more staff to adequately meet residents’ care and activities needs. Their feedback suggested that fewer care staff were being employed than in the past, increasing people’s workloads. They also pointed to a mismatch between residents’ needs and allocated time for their care, all resulting in a negative impact on the service delivered. Through our questionnaire responses, we found that only a fifth of staff made specific reference to receiving dementia training, which may also have implications for resourcing.

Staff also raised issues about their pay and working conditions. We note that Lambeth Council is committed to securing the London Living Wage for staff employed by their contractors, but this has not been implemented to date in the care sector.

Another key factor seeming to affect the quality of extra care services - particularly at Clarence Avenue - is how well the different contractors involved in the service (domiciliary care team, landlord, caterer and activities coordinator) work together. This issue is explored further below, under ‘service integration’.

Safety

All the residents we spoke to said they felt safe in their homes: *“I am safer now because I am away from ‘certain people’”; “I feel safe here; I could no longer look after myself at home.”* This was mirrored in our family survey: all respondents felt that their relatives were safe.

Most families (87%) also felt that they are kept well informed by the care home or extra care facility about concerns regarding their relative. But only half confirmed that they knew the arrangements for their relative at times of emergency. One relative spoke exceptionally highly of the service provided at Alver Bank: *“I have been phoned late at night to be kept informed and assured all is well and which hospital/ward to visit.”*

Resident choice

Whilst it is absolutely right that safety and security is a key priority in care settings - especially for people living with dementia - a number of residents expressed concern that this came at the expense of their independence.



Review of Dementia Services

As one resident with dementia told us: *“I want to be allowed to be my own person again. This is not my life, it is what other people have given me and it is worse than prison.”*

Some residents also wanted more input into decision-making. For example, residents at Charleston House didn't feel as though they had enough input and choice about some of the services and activities on offer. This included influence on the menus, requests for refreshments at the in-house cinema club and care schedules. *“I like my carer but would prefer to be helped to get up and start the day earlier. Often she doesn't arrive until 11am.”*

With the exception of Charleston House, the focus was on services and support coming into the homes and schemes, for example hairdressers. This is of course very practical for frailer residents with higher needs. However, we saw that more mobile residents often had limited opportunity to choose other services in the local community due to transport difficulties and lack of staff time to accompany them - issues also flagged by the service managers.

Activities and trips

Apart from those residents with day centre visits included in their personal care plan, there were no regular initiatives at any of the facilities to take residents outside their home, other than visits to hospital or the GP. We were struck by the extent to which this limited the choice of activities and opportunities for residents to sustain their interests and connections, and contributed to their lack of autonomy. A staff member shared with us the example of a tenant who became *“more and more depressed and begged to move somewhere where there was more contact with people”*.

All four facilities had activity coordinators but a third of the staff who responded to our survey felt that more could be done to increase the availability of activities and the participation of residents. These staff suggested that care facilities should plan more day trips for the residents that could manage them, as many are *“stuck in the home 24/7”*.

At Clarence Avenue residents told us that the feeling of isolation from the lack of activities was further heightened by the remote location of the scheme, with limited access into the community. We noted across all four facilities that, due to staffing pressures, only residents with family or friends were able to go out regularly and none of the schemes had sustained volunteer programmes to facilitate journeys out of the building. The number of residents with family varied: only a quarter of Alver Bank and Charleston House residents had relatives, whereas at Clarence Avenue and Collingwood Court, over 85% had family.

Friendships

Given that we visited people living in group residential settings, we were surprised to find quite a mixed picture in terms of the number and quality of friendships between residents. On the whole, we felt that opportunities to develop friendships were somewhat lacking and, to some extent, this may reflect the lack of activities available. When asked about their friendships, residents said *“Since my wife died I am on my own”* and *“We're not really encouraged to mix together. Not everyone has the ability to communicate.”*

Several family members recognised good relationships with staff but felt that this was not equivalent to friendship. Comments included *“[My relative] generally views fellow residents as*



just that - not close to anyone”, “The only normality is the staff - he needs stimulus. He feels imprisoned and very isolated” and “Knowing the person sitting next to you is not a friendship. Dementia does not allow for this kind of friendship”. Of the relatives who responded to our survey and who weren’t sure or were certain that their relative did not have any friends, half said that their relative was living with dementia.

Given the growing recognition of the links between loneliness and cognitive decline in older people⁷ and the particular dementia risks of depression and lack of mental stimulation⁸, we believe supporting social interaction within residential care settings is crucial - as reflected in our recommendations.

Service Integration

Within extra care schemes

At the extra care schemes we visited, several providers were involved in delivering different elements of the service, with separation between care, housing management, provision of meals and activities. Our impression, particularly at Clarence Avenue, was that there was a need for the different providers to coordinate their work and communicate with each other more effectively to ensure that day-to-day joint working is effective, and able to deliver a holistic service to residents.

A stark example of the impact of this siloed working was highlighted in the experience of a Clarence Avenue resident who was no longer willing to shower when her carer arrived at 11am each day. Her daughter told us that she found it very difficult to get the service providers to address the issue. She was telephoning her mother every morning when the carer was scheduled, to try and encourage her mother to shower. Eventually her mother explained that she didn’t shower because the water was cold by that time. Effective communication between the care provider and the landlord could have resulted in swift corrective action in this case, with immediate impacts on the quality of the resident’s care, as well as increasing the efficient use of carers’ time.

As these Enter and View visits were initially planned to better understand how care was being provided, we did not seek the views of the other service providers at the two extra care schemes. However, we will address this gap in future visits, where we will explore the theme of service integration more thoroughly.

Links with other health and care services

The four facilities all reported working closely with their local GP practices, pharmacies and other services. This was generally supported by residents and relatives. Of those that responded to our survey, we found the majority (70%) of both staff and families were satisfied with the support provided by local health and social care services.

⁷ Boss, L., Kang, D.-H. and Branson, S. 2015. ‘Loneliness and cognitive function in the older adult: a systematic review’, *International Psychogeriatrics*, 1-13: doi:10.1017/S1041610214002749 featured in the Campaign to End Loneliness research bulletin Feb 2015: <http://www.campaigntoendloneliness.org/wp-content/uploads/Campaign-to-End-Loneliness-Research-Bulletin-13.pdf>

⁸ Alzheimer’s Society information on dementia risks: <http://www.alzheimers.org.uk/reducemyrisk>



Despite this general satisfaction, a number of concerns were also raised. Two staff members expressed the need to improve the quality of interaction between residents and the GP, one commenting that *“Sometimes they [GPs] just look to what the nurse says about their condition without an examination, and prescribe drugs”*. Three respondents highlighted delays in care provision as well as a lack of information to make any progress towards addressing the problem: *“My mum needs some physiotherapy. I was expecting the physio team to take her to an exercise centre and walk her round the building but that hasn't happened. I have no contact numbers for the physio team. I don't know how to get in touch with them”*.

The care managers that we interviewed commonly responded that Accident and Emergency departments in hospitals would be their first point of call in cases where they felt that a resident needed urgent health care. No manager mentioned knowledge or experience of accessing the TALK helpline funded by the SLIC programme, which provides direct access to geriatricians at local acute and mental health hospitals.

Wider community links

Our visitors' impressions were that there were missed opportunities owing to the four care facilities working largely in isolation. For example, the facilities were all in the same local area and with similar clients, yet there was no connection between them - no thought of any joint working, or sharing of ideas or pooling of resources. However, they were all thinking about using volunteers, and arranging more activities and outings - areas for potential joint work. This issue was discussed at our dementia review workshop in September 2014, where the managers were encouraged to work together more closely and to share resources (see appendix 1).

We also gained no sense that any of the four facilities were particularly rooted in their local neighbourhood. In our view, these lack of community connections have considerable implications in the light of our concerns around residents' isolation. There was little obvious contact with the outside world in terms of local people coming in to the facilities as visitors or volunteers, apart from a volunteer from the local Catholic church who visits Collingwood Court regularly to assist with activities. Even Stockwell Day Centre, which is run by Lambeth Council and located at 44 Clarence Avenue, seems to have weak links with the extra care scheme next door; only a small number of residents spend time there as part of their care plan.



Section B: Community services for people with dementia in Clapham Park, SW4

To help us build a clearer picture of dementia support in the Clapham Park area, both for those living independently as well as residents of the schemes we visited, we also talked to other key local providers.

GPs

As the first source of advice for most people who have worries about their memory is their GP, we talked to practice managers from four practices in the SW4 area: Grafton Square Surgery, Dr Santamaria Surgery, Clapham Park Group Practice and Hetherington Group Practice.

The information received from the GP surgeries was limited, which may be a sign that more could be done to ensure that health professionals are better equipped to recognise and support people with dementia. Responses suggested that training was patchy - two practices confirmed that GPs were trained in dementia as part of their continual professional development - but otherwise, there was only either basic or no training provided for the wider practice team. Only one practice was very clear about the number of their patients living with dementia, all of whom were well known to practice staff. The other three practices indicated that a small proportion of their overall patient list had memory problems but could not be more definitive.

We were also keen to hear how integrated care managers (who are being placed in GP practices across the borough to support person-centred care) are contributing to dementia services in Clapham Park. However, at the time of our review none of the practices we spoke to hosted anyone in this role - although one placement was imminent and another practice was due to receive a briefing on the scheme.

Memory Service

GPs can refer patients to the Lambeth and Southwark Memory Service for assessment, diagnosis and treatment for mild to moderate dementia. The service is key to the care pathway - especially as an early and prompt diagnosis is crucial to giving people living with dementia a greater chance to improve their quality of life.

From the information we gleaned, the Memory Service appeared overstretched with lengthy waiting times for assessment and treatment, despite low referral levels. The service receives approximately 25 referrals a week (mostly from GP practices) across the two boroughs. This has increased by 40% over the past year but we were struck by how low these referrals were, given the prevalence of the condition. The service had reduced its waiting list from 237 to 60 from June to December 2014, but patients still wait for 11-12 weeks for an initial assessment and a further 7-8 to complete the diagnosis. This is longer than average according to the national map on the Department of Health's dementia challenge website (although the wait for the service at Guy's Hospital is shorter than average).⁹

⁹ <http://dementiachallenge.dh.gov.uk/map/>



Specialist multi-agency networks and partnerships

Stakeholder interviews with representatives from the Southwark and Lambeth Integrated Care (SLIC) and the Health Innovation Network (HIN) dementia programmes suggested a shared view that there is a long way to go before truly integrated services become a reality. While both programmes are focusing on care homes and progressing well, we noted a lack of collaboration and sharing of knowledge between these initiatives. In addition, our own participation in the SLIC programme has highlighted an opportunity for work to be shaped more directly by the real experiences of patients, their carers and care providers to ensure outputs are fit for purpose. We see this as an area that Healthwatch could make a significant contribution to in future.

The voluntary and community sector

The Memory Service is the main source of referrals to the Alzheimer's Society's Dementia Advisors who provide information, advice and support to individuals with dementia and their carers. The Society's Lambeth team told us they have supported a total of 16 individuals with dementia and 11 carers from SW4, which again seemed low, even given the number of referrals handled by the Memory Service.

The dementia advisors listed the key concerns their clients have about local services:

- Variable responses from GPs in discussing memory problems
- A long wait for assessment by the Memory Service
- Lack of advocacy or befriending support for people with dementia
- Lack of affordable/accessible transport.

Carer views

Family carers for people with dementia who attend the Healthy Living Club in Stockwell, (some of whom live in the Clapham Park area) had mixed experiences of services and a range of views about both what was offered and what was missing.

All felt that they had suitable access to appropriate dentists and opticians, and several commented on the good service at the Memory Clinic at King's College Hospital.

Their key concern was around the lack of easily accessible advice and support following diagnosis of dementia. The carers felt they were expected to seek out support for themselves at what is already a difficult time, and they do not always find it easy to identify the right sources of help. Our focus group participants did not mention the Alzheimer's Society dementia advisors.

The carers identified a need for automatic referral for a social services assessment and support for carers to ease the process of getting the right help. They also pointed out the need for regularly run services as many support groups or activities are currently time-limited or intermittent: *"Singing for the Brain is excellent but it was only offered for a short time and I've had to search for other activity programmes and ask whether my husband qualifies for them."*



Community awareness

The UK government's five year national dementia strategy¹⁰ (2009-2014) and Prime Minister's newly extended challenge on dementia to 2020¹¹ identify the need for the public to have better knowledge to support people diagnosed with the condition and also to remove the associated stigma. We also believe that as councils adapt their care models to encourage people with dementia to live longer in own their homes, the local community is likely to be drawn upon as a resource to support and sustain this model of community-based care.

We attempted to test out levels of community awareness of dementia in Clapham Park as part of our review, but received no response to a questionnaire we distributed in GP practices and other venues to solicit local views on dementia services. We suspect this suggests - unsurprisingly - that people who are not directly affected by dementia give little thought to it. Similarly, only two people of a small sample of 25 passers-by at the Holy Trinity Fair in July 2014 had any knowledge of dementia - both had relatives living with the condition.

In the same vein, all four local churches that we talked to as part of the review told us that they were in contact with one or two congregation members with dementia who lived at home. But none of the parishes were involved with any specific work for local people living with dementia.

"We keep an eye on her and make sure she can follow the church service, though sometimes she gets annoyed with us" Local vicar

¹⁰ Department of Health (2009) Living well with dementia: A National Dementia Strategy. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf (Accessed: 13th February 2015).

¹¹ Prime Minister's Challenge on Dementia 2020: <http://dementiachallenge.dh.gov.uk/>



Key Issues and Recommendations

Healthwatch Lambeth has identified two key issues from our review:

Issue 1: Social isolation

We are concerned that residential schemes for older people do not seem to be commissioned, designed or delivered to address the risk of social isolation and loneliness. While we found individual care managers who believed that “*care support must be about facilitating residents’ access to services and opportunities*”, living in this type of housing does not automatically solve social isolation on its own. And our findings suggest it may even exacerbate the problem. The review team was especially struck by the amount of resident feedback reporting lack of friendships, absence of activities to encourage interaction with each other, and isolation from the local neighbourhood and community. We appreciate the increasing pressure on care budgets but strongly feel that if this issue is left unaddressed, increasing social isolation is likely to contribute to higher levels of dementia and mental illness amongst the growing older population.

Providers need to involve and empower residents in residential care settings to find creative and innovative ways to build and sustain relationships and connections. Domiciliary care workers are a potential resource for reducing social isolation, for ensuring people have access to information about other services they may need, and to act as important channels of communication. Volunteer schemes could also be fruitful for boosting community links with care homes and extra care schemes.

There is a rapidly growing body of knowledge about both the impact of social isolation, and successful ways of reducing isolation. We believe Lambeth Council and the Clinical Commissioning Group need to engage with these debates, to look at what we can do throughout the borough to reduce the risk of isolation and its impact more widely. We believe there is interest and opportunity to build on existing resources and assets in the community alongside services.

Recommendations

- 1a.** The local authority should stimulate and if necessary resource a forum to encourage care providers and their activities co-ordinators to share, learn and promote joint working.
- 1b.** Commissioners should ensure that opportunities for meaningful social interaction are an integral part of contract specifications for all residential care facilities, and feedback from residents should be included as a key performance indicator.
- 1c.** The local authority, volunteer organisations and care facilities should explore the viability of a new volunteer visitor programme to create stronger links between the local community and residents living in residential care settings.
- 1d.** Extra care scheme providers should test new configurations of care staff teams to maximise relationships with residents.



Issue 2: Vision and leadership on dementia

Our review found low levels of dementia training among health and care professionals, information access issues regarding support for those affected by dementia and their carers, and a lack of public awareness about the condition. This leads us to believe that there is a need to improve the dementia knowledge and skills base within Lambeth. It is crucial that Lambeth citizens and service providers are able to detect and understand dementia to ensure dementia patients and their carers have timely access to treatment and support, as well as enabling these members of our community to enjoy a good quality of life.

No individual or organisation we spoke to expressed or recognised any sense of leadership about dementia services. Our research in the Clapham Park area identified a range of services in existence but no joined-up approach to the care of people with dementia in the local area. Commissioners also acknowledged, as the SLIC and HIN representatives did, that to date services have not been designed or commissioned to provide an integrated service.

We believe that the strategic leaders in health and social care in Lambeth need to take a more proactive and ambitious position on services and support for people with dementia. The leadership in this area rests with the Health and Wellbeing Board, who need to champion dementia services and encourage coordination and communication between stakeholders. We could learn from interesting initiatives such as the Dementia Action Alliance in Southwark (launched December 2014) that facilitates collaborative work between organisations and individuals to support people living with dementia to remain a valued part of the community and live a full life.

Recommendation

- 2. Health and Wellbeing Board should lead on establishing a Dementia Action Alliance for Lambeth.**

Healthwatch Lambeth commitments

We acknowledge that our initial conclusions on the state of dementia services in Lambeth are drawn from a limited sample, and we are very conscious that there are many people who we did not reach and hear from. We plan to extend our work in 2015-16 by committing to:

- complete our Enter and View visits to all extra care schemes in the borough (with a particular focus on social interaction opportunities for residents and collaboration between on-site service providers)
- gather views and experiences from: people with dementia living independently and using domiciliary care services; and domiciliary care providers
- document people's experiences once they have been referred back to their GP practice by the Memory Service
- collate and share service user feedback with Southwark and Lambeth Integrated Care Programme, Health Innovation Network Dementia Programme and commissioners.

March 2015



Appendix 1

Dementia Workshop - September 2014

Healthwatch Lambeth held a workshop which was attended by 42 people, including Healthwatch members, carers of people with dementia, staff from some of the services we had visited as part of our dementia review, and representatives of other local organisations. The Enter and View team presented their initial review findings and then the participants worked in groups to discuss key elements of services and support for people with dementia and their carers in Lambeth.

The key issues raised were:

1. Information, training and raising awareness:

- The need for joined up services so that good practice and learning are shared.
- Need for effective communication between services around an individual's needs
- Use of Life History/ Individual Story and Profiles to shape the social culture in care service
- Possibility of shared training for both paid and unpaid carers on a range of topics including communication with people with dementia; lifting and handling safely; talking about financial matters and supporting people to regain mobility after a fall?
- Increase community awareness about importance of early identification, awareness of early symptoms and generally encourage people to go to their GP
- Do GPs need further training on early symptoms and on local services?
- Address fear and anxiety that prevent people seeking help, change language to focus on "Memory Issues" rather than Dementia.
- GPs to share data and involve PPGs.
- Role of pharmacists in early identification

2. Residential facilities working together

- IT Provision: to increase social interaction via online games; skype phone calls; in communal areas and with a training programme.
- Better use of communal areas - need to be attractive, bright and pleasant spaces with plants, raised beds and gardening projects, decent clean chairs to sit in; activity provision using local community to help, local schools etc.
- The four care organisations in SW4 could work together to map out what is available in the community, using resources such as Age UK Lambeth directory
- The Activities Co-ordinators could share ideas and resources
- Create a network, support each other and plan joint events
- Negotiate together to have greater clout, deals with providers of services, advertise for friends and give joint training

3. Community Action

- Look at better use of IT for information, communication and learning
- Transport and mobility - identify accessible transport, provide information for both care home residents and people living in their own homes



Review of Dementia Services

- Raising general community awareness through Dementia Friends campaign - public health posters in public places especially bus stops, transport locations.
- Raise awareness through sessions in schools and youth clubs.
- Strength and Balance classes in the community for older people including those with dementia
- Befriending services in the community with specialist knowledge of dementia
- Joint initiative with the police and/or community safety officers to develop care plans and strategies to manage times of risk e.g. when people with dementia can't find their way home.



Healthwatch Lambeth

336 Brixton Road
London, SW9 7AA

Tel 020 7274 8522
Text 07545 211 283

info@healthwatchlambeth.org.uk
www.healthwatchlambeth.org.uk/enterandview

Registered charity no: 1153444

Registered company in England and Wales no: 8430436