



Review of dementia services for people living independently and family carers

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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



Introduction

Following a review of dementia services for people living in care homes and extra care schemes (with 24 hour on call support) in the Clapham Park area in 2014¹, Healthwatch Lambeth carried out a follow up investigation in summer/autumn 2015 to gather views on services for people living with dementia independently in their own homes.

Objectives

Our investigation aimed to understand:

- The support needs of people living with dementia and their carers
- Their experience of using health and care services, and to what degree these services worked in an integrated way
- Their perceptions of any barriers to accessing services
- Their views on gaps and areas for improvement.

Methodology

Between August and October 2015, we carried out in depth interviews with family carers and people living with dementia across the borough. Of the 21 interviewees we spoke to, 18 were family carers and three people had dementia. We spoke to people over the phone or face-to-face.

Interviewees were recruited via the Carers Hub Lambeth (2), the Healthy Living Club (10), Streatham Dementia Club (7), a local authority day centre (1) and a Southwark and Lambeth Integrated Care dementia meeting (1).

Of the three people we spoke to who had dementia, two interviews were held at the Streatham Dementia Club (plus a follow up interview with one person with their family carer at a later date), and we conducted one brief telephone interview with someone attending a day centre who responded to a letter we had provided for family carers.

We focused on how well services work for people after they have received a diagnosis of dementia. We asked about:

- Information and support at the point of diagnosis
- health and care services used by the person with dementia
- other activities they take part in
- support for the family carer
- the quality of life for both the person living with dementia and their family carers.

¹ Review of Dementia Services in Clapham Park SW4: www.healthwatchlambeth.org.uk/news/dementiareview



Limitations

We had also hoped to talk to people receiving support from the Alzheimer's Society but this did not prove possible in the time available. As all but one of the interviewees we spoke to were currently accessing or had experience of some form of dementia support service, our findings do not capture the views of those without such connections. With around 1,500 people estimated to be living with dementia in Lambeth, we acknowledge our investigation reflects a very small proportion of experiences.

Interviewee profiles

Most of the family carers we interviewed were currently supporting their relative with dementia but one relative had died in the past year and three had moved to a care home or now lived with another family member.

Carers described the current severity of dementia experienced by their relatives as follows: mild (2), moderate (9), severe (4), fluctuating (1), with the conditions of two relatives unspecified.

All but two of the carer interviewees were or had been principal carers. The caring responsibilities people described were considerable, for example eight carers lived with their relative (five with no other household members) or regularly provided night cover. One carer was looking after two parents with dementia. Most carer interviewees were supporting a parent, while one cared for their grandparent, one lived with her husband and two carers supported their siblings. Two interviewees described themselves as self-funders.



Findings

Information and support at diagnosis

Four of our interviewees' relatives had been diagnosed in the past two years by the South London and Maudsley (SLaM) memory service, with one other person waiting for a diagnosis from the service at the time we spoke to them. Others had received a diagnosis between three and 10 years ago. In total, 12 families had experience of the SLaM service.

SLaM Memory Service

Six interviewees including two people with dementia gave positive feedback about the information and support provided by SLaM when they received their diagnosis. Comments included: *'Extremely helpful'*, *'Everything was explained - the staff at the Maudsley Hospital were good and helpful'* and *'We got what we needed'*. The interviewee whose two parents both had dementia described how the service representative explained her father's results carefully and clearly to him. The representative also spelled out the need for domiciliary care to support his wife who had been living with dementia for the past eight years, as he had been reluctant to accept this before his diagnosis.

Two interviewees said their relative received a home visit from the service during the diagnosis process. Another person told us an Italian interpreter had been provided for her mother, which had worked well.

Others were more ambivalent, for example: *'SLaM was not totally unhelpful - they referred us to social services and the Healthy Living Club'*. One person living with dementia and her family carer said she had attended a six week course on living with dementia run by the memory service, which had provided useful tips such as putting picture labels on cupboard doors. But there had been no follow up afterwards.

Four interviewees felt they didn't receive appropriate details from SLaM - either too little or too much. Comments included: *'They just told us she had Alzheimers - they didn't give any other information'* and *'I was given lots of paperwork and told that the later stages of dementia gets worse - I felt I already knew that'*. One carer said her family was still waiting for a definitive diagnosis a year on from the initial assessment. She told us her grandmother had had numerous tests and appointments but gaps between communications were long: *'Everyone is vague - a confirmed diagnosis would be helpful - it would tell me what type of dementia she had, explain things in more detail and provide suggestions for the future and how things may deteriorate.'*

Another carer whose relative was awaiting initial test results told us: *'I've had no information so far. They say "not now". I want the memory service to be honest and give me some coping mechanisms.'*



Another carer told us he had a particularly difficult experience with the service, describing how, at the beginning of the diagnosis process, SLaM and council social workers did not listen to his views and forced him out of his mother's house. After his mother was admitted to hospital several months later, he returned to the house to find it in severe disorder and dirty as his mother had become incontinent. He had to clean the property: *'It was distressing - completely wiped me out. SLaM didn't do their job - they shouldn't have let her get to that state.'*

A different carer whose relative had other mental health needs as well as dementia told us his mother's depression was not taken into account and he was disappointed that SLaM did not address his mother's conditions in a holistic way. He also felt that once his family had decided to take his mother off her dementia medication because it gave her diarrhoea, she was discharged from SLaM without any other offers of support or information.

Other memory services

Three interviewees had received a diagnosis from services outside the borough and one person had been referred to the memory service at St Thomas' Hospital, describing it as *'Absolutely amazing and fantastic. They made sure we understood everything.'*

Services used after diagnosis

In this section, we detail people's experiences of health and care services after receiving a dementia diagnosis. Feedback on individual services was mixed, but across the interviews we carried out, we detected considerable frustration with service liaison - both within and between different teams, as well as delays with equipment and essential supplies. Experiences of individual services are described below.

Care assessments

Nine people told us their relative with dementia had received a care assessment, but four said the process was not carried out properly or was delayed. One person described waiting five months for her mother to have her first assessment. Another said no one explained what would happen beyond the initial assessment her mother had received after being discharged from hospital for a fall.

A third person said his mother had never received a proper assessment and those that had been carried out contradicted each other, making it difficult for the care coordinator to know which one to follow. Another family carer felt the assessments her mother had received were rushed: *'At the last assessment, the worker didn't even have a notebook to take notes. It's difficult to get the assessment changed when it's incorrectly reported.'*



One person with dementia had been described as ‘aggressive’ in her assessment but this information wasn’t shared with her son. This caused problems when he was choosing a respite care placement, as the first home he chose refused to take his mother because of the notes on file, which he was unaware of, causing confusion and frustration.

One other person had received an assessment and was offered advice as a self-funder. In contrast, a different carer whose parents were also self-funders told us that when a GP requested input from social services, they visited four times but *‘they can’t help - they don’t want to know.’*

Two family carers told us their relative had never received an assessment. One said: *‘They sent us some forms but no one came to talk to us - to be honest, my sister didn’t want more people around’*. Another preferred for her mother not to have a financial assessment, explaining *‘It’s too intrusive.’*

Social workers

Interviewees’ experiences of social workers were largely negative. The seven specific comments we received included four strong criticisms from family carers who were very disappointed and frustrated by the service. As previously described, one person felt social workers ignored and excluded him during his mother’s diagnosis while another described the service as *‘rubbish, neglectful and negligent’* because he felt workers didn’t address his mother’s needs, adding *‘They don’t like being challenged... It’s very stressful’*.

Another person told us: *‘The service is appalling - apart from one person... I’ve experienced huge reluctance to help us. I’ve been unhappy with the service for the majority of the time.’* The fourth carer told us the slow response from social workers made him *‘loath to ask for help’* despite having his own health concerns. He contrasted the Lambeth service with Hackney, his own borough, which he described as *‘much better - more proactive’*.

Several people also flagged that they had difficulty making contact with social workers. One carer told us they didn’t know their social worker’s name and had to ring the main Council phone number to get in touch, while another told us that social services had promised a date and time clock for her sister which never materialised: *‘They visited two or three times, but the clock has never come. I have no idea who or how to chase this up, no one left contact details.’* A third carer wasn’t informed when his mother’s social worker was changed and a fourth commented: *‘You’re never able to get hold of anyone... I was continually chasing them.’*

One person’s view was more mixed: *‘There’s a long response time for social services - you need to find the right person to process the query - it’s complicated. They’re thin on the ground. But they’re not bad. They’ll spend an hour and a half talking to you. We’re very lucky - they’re good in Lambeth.’* A seventh interviewee also felt the service was responsive to their relative’s needs, particularly around assistive technologies.



Domiciliary care

Twelve of the people we interviewed had experience of domiciliary care. Only three, including one person with dementia, said they were happy with the service: *'Dad likes them going in'* and *'The carers are very good - they understand mum. We've had the same carer for two years - she knows mum well and how to deal with her. We've also had another young carer for a short while who's very good despite her lack of life experience'* and *'My carer looks after me - she rings my daughter if she has any concerns.'* Another family carer told us paid carer hours had been increased in response to her father's increased needs but did not comment on the quality of the service.

However, most (10) other interviewees all reported current or previous problems with domiciliary care. Five people said they were (or had been) unhappy with the quality of the service and a sixth implied so. Comments included: *'The carer was meant to do washing and shopping - my sister read their instructions - but they didn't'* and *'My mum was dressed [by the carer] inappropriately for church once - she wasn't dressed up. I found that really upsetting'* and *'It's good for me to wash my mum on the other three days a week [when the carers don't come], to do things like clean her toes properly.'*

Four people flagged a lack of service consistency, with too many different carers coming into their relative's home: *'The agency sent a different person every day so you had to explain tasks each time.'* Three comments related to a lack of time for carers to carry out their tasks and another person told us carers were often late due to being double-booked. The family carer explained the knock-on effects of this, such as missing community transport: *'I end up having to take her to the day centre and I cover weekends myself now - it's less stressful but not sustainable.'* One person also said his mother's care hours had been reduced, which he was unhappy about, as he felt he was already under too much pressure as a family carer: *'They're taking the mick.'*

Two people were concerned that workers did not have a caring attitude and one felt they weren't adequately trained in dementia care. Three people had swapped providers or found an alternative, such as employing a personal assistant. *'Finding our own service was better and less expensive - we got the same person where possible and the quality of care was better; they really did seem to care.'*

Another two interviewees had been offered domiciliary care but turned the service down: one carer preferred to do tasks themselves and the other was deterred by the quality of service her neighbours received from paid carers.

Respite care

Three family carers told us their relative received respite care at home during the day. One relative was taken out for coffee and on bus trips around London. Another family member appreciated that her mother's carers were from the same culture as her, as this brought particular understanding around certain things such as calling her mother 'aunty'



as a mark of respect. As with domiciliary care, two family members felt consistency was important in building a relationship with the person with dementia.

Two interviewees said their relative had spent some time in care homes to provide short-term respite but neither were positive experiences. One carer said: *'The care home staff took my mum's verbal aggression personally - they need dementia training.'* The other told us: *'I couldn't visit her too much because she got upset, so I'm not sure how it went but the care home doesn't have a good reputation.'* Another family carer told us they wouldn't consider residential respite care because of the distress it might cause her mother.

GPs

Eleven people commented on their GP, including the three people we interviewed who were living with dementia. The majority (9) reported a good service because they felt the GP had got to know the person with dementia well. Comments from family carers included: *'Wonderful, very impressed - she has got to know my mother and so understands the situation'* and *'very supportive'*. Two carers also mentioned that the GP was always prepared to do a house visit. And one person told us the practice nurse was *'very good'*. Interviewees with dementia told us: *'The doctor is marvellous - I always ask for the same one. I was on medication but the doctor stopped it - I feel better for being off the medication'* and *'My GP is quite good at helping'*.

One person with dementia and her daughter were more ambivalent: *'The GP is OK but sometimes it takes a while to understand what is being said'*, adding *'The doctor listens though'*. Only one interviewee reported that their new GP was unhelpful and not proactive: *'They don't phone to see how she is, but this is someone's life. Our previous GP knew my mum intimately.'*

District nurses

Three carers talked about their interactions with district nurses; all had poor or mixed experiences. One person said *'The nurse is meant to come to apply cream twice a week but we barely see her'* and another carer told us she treated a sore on her mother's bottom herself because the nurse turned up without an appointment and was rushed: *'Their minds aren't on the job'*. However, the carer later added: *'When the service does arrive it's great and understanding - it's good on the ground, people do care. But it gets lost at the other end. The service is so big, people don't know where they are any more.'*

Two of the carers also described difficulties obtaining appropriate incontinence pads through the district nurse team. One was told that the supplies for bowel incontinence were only available for housebound patients and even when the GP re-referred to the service again, although more helpful in their manner the second time around, the nurses told the carer the necessary pull up pants were not available on the NHS. The other carer, when requesting heavy duty supplies to see her mother through the night, was told



they were only available to bedbound patients and she should wake her mother up to change her; *'But that's no good for someone with dementia! I'm hardly trying to rip off the state by asking for more incontinence pads.'*

Adaptations and equipment

Carers reported a range of difficulties in obtaining appropriate equipment for their relatives. For example, three people with dementia needed help getting into the bath but one carer was given a step that was useless because it was too steep, while another wasn't offered any proactive solution: *'We'd be more than happy to pay for it but can't they help with recommendations?'*

The third person had applied to a council fund to have a wet room fitted, explaining *'There's an 8 inch drop from the side of the bath which is dangerous and my mother's itchy because she can't be washed properly.'* She heard about the fund through her domiciliary carer but had been warned the application was likely to take 10 months.

Another carer described how it had taken over two years for a housing association to install a wet room in his mother's flat. During that time his mother had to sit in the kitchen and get washed down, which he felt was undignified. They later received compensation for the stress and anxiety the lengthy process caused.

It took another carer a month to get a commode when her bathroom was being refitted. She told us no one knew how to resource one: *'It didn't help my stress levels.'* The carer did add that stair rails and a shower had been fitted successfully however.

Grab rails were requested by another carer: *'We waited eight months for an OT but no one turned up - they hadn't put a referral in. My mum was going to have an accident so I fitted grab rails myself.'* The carer told us: *'The same thing happened with the bath chair and raised toilet seat - I had to contact the equipment team directly.'*

One family had asked for a walker six months ago *'but we haven't heard anything.'* Two people had requested a wheelchair to increase their relative's mobility. One person described the occupational therapist as *'very very good'*, recognising that her mother required a weighted wheelchair, although a standard one had recently been delivered in error and needed returning. When the other carer requested a wheelchair for his mother, she was offered physiotherapy instead but the carer explained to the social worker that it hadn't worked in the past. The carer later accepted physiotherapy with a wheelchair, along with a three month wait for delivery.

Only one other person mentioned physiotherapy, describing the six week course arranged by the GP as *'Brilliant - of great benefit. It improved my mother's mobility getting in and out of her chair and enabled her to walk down the corridor.'*



Assistive technologies

Three people mentioned using assistive technologies with mixed responses. One carer arranged for sensors to be fitted for safety reasons when her mother was still living on her own but her mother didn't like them so had them removed.

Another carer described the need to have a trial and error approach to finding solutions. For example, she did an internet search to find alternatives to standard dosette boxes to ensure her mother takes her tablets correctly. She found a pivotal box on a timer linked to Careline but in the end arranged for the domiciliary carers to ensure her mother keeps to her medication regime. Her mother also had a GPS buddy for her handbag and a non-removable watch which both worked well.

The same family found a talking clock didn't work for their mother but a clock with the date and time on it prevented the person with dementia phoning her family in the early hours.

One carer also told us that she appreciated how the OT recognised her mother's reluctance to use most technologies.

Rapid Response Service

One carer had received support from the Rapid Response Service following a referral from her GP after the carer reported shoulder and foot pains from lifting her parent in the course of routine care tasks and after falls. The parent also had bouts of violence and incontinence, making the carer responsibilities particularly arduous. The carer rated the service very highly: *'The team were brilliant, they sorted everything out. They got my father a suitable commode and a recliner chair which tilted up and forward so that he was almost standing up. They recommended that he get evening care, and that two people should attend to him. They got him a hospital bed for his room and a trolley for meals. They were great.'*

Older Persons Units

The Older Persons Units at King's College Hospital and Guy's Hospital also received positive feedback from carers. One carer who was still waiting for a definitive diagnosis for her relative described the King's service as the most useful and helpful of the agencies she had had contact with to date. *'They would help whenever I had a query but my nan's been discharged now so I'm unable to ask them things anymore.'* Another person who had been referred to the service by her GP after her daughter requested physiotherapy for her mother after a fall, had participated in a fitness and balance study run by the Unit. The daughter told us: *'The unit team were very nice and offered a special bed but I wanted to keep things as normal as possible.'*



Another carer described how her mother was referred to the Guy's service following a 'meltdown' the previous winter, when her mother became unresponsive and stopped eating and drinking. She said *'The team spent well over an hour with us. They were very respectful to us both. No stone was left unturned. They referred us to the OT and district nurse. They offered to follow up with me - they were honest about my mum's terminal condition - it's what you need for thinking ahead.'*

Hospitals

Three people told us about their experiences of hospital stays that did not relate to dementia. Although unable to tell us which service they had used, one person living with dementia told us about their two week stay in hospital for an operation: *'It was lovely being in hospital - the staff were supportive.'* One carer described St Thomas' Hospital as very good: *'They treated mum well - can't fault the Trust'* but had concerns about the clinical care at St George's Hospital. Another carer told us her mother didn't receive any follow up after a stay at King's College Hospital following a fall: *'I would have welcomed it - I might have missed something.'*

Community Mental Health Teams

One person whose relative has dementia with Lewy bodies praised the mental health worker who provided ongoing support after diagnosis: *'She's wonderful, she was part of the family, genuinely concerned for my husband's health and how to improve it. I could ring her any time and she returned my calls. We trusted her and got on well - that's half the battle'*.

Alzheimer's Society

Most comments about the service offered by the Alzheimer's Society related to the carers group and training mentioned later. However, one person with dementia told us the Alzheimer's Society had got in touch but she didn't receive regular contact from them. Another carer said her relative had received a home visit from them, which led to a referral to social services.

Day centres, clubs and activities

Eight interviewees talked about the two council-run day centres. Four people gave positive feedback on the service they used: *'The key worker from the Clarence Avenue day centre visited and spoke to us before my mum's first day - she was really good'* and *'Clarence Avenue is great'* and *'At Central Hill the vitality's high.'* One person with dementia told us *'I enjoy it - I go on sight-seeing trips'*.

Others were ambivalent about these services or had particular concerns, for example, one person was glad that Clarence Avenue day centre was able to take people out for trips but wished the Healthy Living Club could offer the opportunity too, adding *'We prefer the*



club. Another family carer had made a complaint about the safety of the transport service to and from the day centre, as operatives weren't securing his mother in her wheelchair before moving her.

A couple of family carers talked about the importance of finding somewhere with the right atmosphere. Comments included: *'We tried Clarence Avenue day centre two or three years ago but it was small, cramped, not right, I felt uncomfortable. My mum needs stimulation. I wanted to be able to pop in but they said no'* and *'We tried two day centres but mum thought she was being left in a care home - she didn't like it.'*

In contrast, feedback on the Healthy Living Club and Streatham Dementia Club was universally positive.

Of the seven responses to the Healthy Living Club, comments included: *'It's a wonderful, wonderful club. There's a joyous feeling about it. The people are fantastic and so happy. My mother loves it'* and *'There isn't anywhere else that cares like this. This is the place to be'* and *'It's the best thing we've ever done... People can just be themselves. No one bats an eye if you drop your fork 20 times.'*

The three people who fed back on the Streatham Dementia Club, including one person with dementia, told us: *'I enjoy it - they look after us. The exercises are very good - keeps me fit. It's very calm and nice'* and *'We had a good sing-song, we always knew the tunes and stayed to have tea'* and *'We both enjoy it, it's very supportive.'*

Three people said their relative attended church groups including an over 60s club and others that ran occasional day trips. One other person told us their mother had tried a church group *'but my mum said it was ghastly'*.

One family carer said that she used to take her mother to the Vida Walsh Centre but withdrew her relative after a while because her support needs meant *'it wasn't fair on the other attendees.'* Another carer told us she went with her sister to the Darby and Joan Club at Woodlawns Centre every week, along with shopping trips, lunches and outings.

Individual family carers also reported that their relatives took part in other activities such as a disability group for partially sighted people, events run by the sheltered unit where the relative lives, Probus meetings (a club for retired professionals), a choir and Singing for the Brain: *'We loved it - it was only for seven weeks but stretched to 11 weeks - we would have kept that up.'*

Friendships and other support

When we asked about friendships and other forms of informal support, only two carer interviewees said their relative maintained friendships. One told us: *'She has an enviable social life.'* One person with dementia also told us she was thinking of joining a knitting



club with a friend. But other carers told us: *'Friends don't really see my mum anymore because of her condition - it upsets me - mum was there for everyone - perhaps they don't understand the condition'* and *'Her friends don't understand what's happening to my mum. They don't see her much anymore. My mum gets very upset about it: she thinks people think she's mad.'*

Two interviewees expressed disappointment that their relative's church congregation no longer keeps in touch: *'People didn't ask about the situation or how they could help'* and *'No one from the congregation visits. I'm quite disgusted there's no contact.'*

One person described the wardens in their relative's sheltered unit as very supportive. Another interviewee with dementia told us he knew his neighbours and a carer also mentioned her father attended Probus meetings with his neighbour.

Support for carers

The caring responsibilities of the family members we interviewed were universally intensive. Almost half (8 of 18) lived with the person they cared for or shared night duties with other family members. For example, one carer travelled from his home in East London to spend six nights a week with his mother, while another carer's brother was moving into the family home with her to share the responsibility. Eight carers described their situation as stressful.

One carer told us they had physical and mental ramifications from their care burden, receiving talking therapy to deal with stress and physiotherapy to deal with pain in her feet, back and shoulders due to the strain of lifting her relative. Others had pressures from additional family care responsibilities and four carers described having to stop work or reduce their hours. Two others mentioned how lucky they were not to have to work, enabling them to focus on their carer role.

Several family carers spoke of the importance of providing the core support to their relatives themselves. *'I was told she had 6-8 years to live and realised I'd never spend the same amount of time looking after her as she spent looking after me so I put my life on hold to care for her'* and *'My mother knows she is in safe hands with her son'* and *'It's difficult but we wouldn't have it any other way.'*

Only one of the interviewees whose relative's condition was mild and was still living independently, gave the impression that their role was not burdensome. However, even this person talked of phoning her relative several times a day and structuring her weekly routine around her sister's needs. In addition, one other person told us she enjoyed her experiences as a carer.

Here are the sources of support that carers told us they relied upon:



Carers groups

Six people told us they used the Carers Hub services, three via the Healthy Living Club carers group. Five valued the opportunity to meet with others in similar situations: *'It's marvellous - people give feedback and ideas for coping mechanisms'* and *'We can laugh at and with each other. We're always sharing information.'* and *'It makes you feel it's manageable and points you in the right direction.'* However, one person had mixed views: *'I can share experiences but sometimes it's a waste of time - I don't go regularly.'* One person who was signposted to the Carers Hub during the interview with Healthwatch told us later: *'[The Carers Hub worker] is absolutely wonderful. She'll be someone I can come back to when I hit a brick wall.'* Two other people said they had heard of the Carers Hub but were unable to attend sessions due to carer commitments, and one told us she may start using the service if her relative deteriorates.

Two people had attended the Alzheimer's Society carers group, describing it as *'useful and informative'* but one told us that she stopped attending the group once she got enough out of it as she had to take time off work to attend. She added: *'[The worker] was really good - you could always ring him for advice'*. Three people attended the Society's six week course, although one person did not have the time to complete the programme. All gave positive feedback: *'very helpful, with lots of information.'*

Two carers who didn't attend carer groups said they largely relied on their own judgement about how to support their family member with dementia: *'We worked out not to contradict mum if she's in a different time'* and *'Mostly I use my instinct. I know I should keep to a routine.'*

Other sources of information

Six family carers told us they had done their own research, using the internet and books. One person mentioned receiving leaflets from St Thomas' Hospital and Age UK. One person said they had been signposted to groups by the council's disability team and another by the Alzheimer's Society. One person told us they were a Dementia Friend but added *'I didn't know you could do training'* and another mentioned they had seen an advert for the scheme on TV.

Three people highlighted the benefits that working in the health and care system offered them: *'I do a lot of bouncing off others at work - colleagues have clients in similar situations'* and *'I use my personal knowledge as an OT. I'm able to chase things. I feel sorry for others who don't know the system.'*

Twelve people talked about entitlement to services and benefits. Five people, including one person with dementia, told us they did not know what they were eligible to receive. Comments included: *'We still don't know mum's entitlements - her tax benefits were stopped during the assessment process'* and *'I've backed off getting support because it's too complicated'*. Two people mentioned direct payments for personal budgets - one



person described the system as *'very smooth'* but the other told us *'It looks an absolute nightmare as you have to keep all your receipts. It would be a good opportunity for my husband and daughter to go to see Bromley play though.'* Two carers said that they had been told that claiming additional benefits would affect their family's current allowances so they did not pursue their claims.

We did not get a clear picture of how many of the carers we interviewed had received assessments themselves. Only one person told us they had received one and three people said they had not.

Other support

Four people mentioned the value of friendships: *'They provide support and are understanding of the situation, some friends have had similar experiences'* and *'You're able to vent with them.'* But one qualified the support friends could offer: *'They're kind and understanding but only as far as you can push it'*.

Seven people told us about the family support they received. Input varied, with some providing assistance with tasks such as cleaning or emotional support: *'We stick by each other'* and *'I can pick up the phone to my cousin and say "today's been bad"'*. Others received limited support such as occasional visits and one person explained that family politics affected the amount of help her sons offered.

One carer also told us that singing in the church choir was her break: *'You need to enjoy the moment when you're out'*.

Service gaps

In addition to asking how well services were working, we were also interested to hear views on how life could be improved for people with dementia and their families.

More respite

Increased carer respite time was top of the list, with 10 family carers identifying this as their biggest need. Six people told us companionship for their relative was an essential element to having additional carer cover: *'A person to get to know my husband and go for walks or to the cinema'* and *'Being able to see a variety of people - not being together all the time - it's not good for either of us'*. Three people specified that they would like more help with household cleaning tasks rather than personal care for their relative: *'I need a maid!'*

More activities

Four people mentioned they would like to access services they already use more regularly; two specified the Healthy Living Club and two wanted more day centre sessions. Two



people with dementia also told us about particular activities they would like to do: knitting and gardening.

Increased carers allowance

Five people told us that the carers allowance should be increased to reflect the real costs involved, such as petrol costs and electricity bills from the constant washing involved with incontinence. One person wanted to see the return of the Fix-Yourself-a-Break scheme. Two interviewees advocated for more flexibility in how they could use their allowances or entitlements. For example, one carer explained they would like to be able to book additional sessions at a day centre for her mother in place of the residential respite she was entitled to. The other person couldn't understand why she wasn't able to receive help with household cleaning instead of personal care for her relative, which she preferred to do herself.

Better information provision

Several carers wanted better signposting and information provision in specific areas such as dealing with financial and safety risks, as well as general information on services and activities for older people. Two people told us they would like help with transport and two people said they would welcome training on coping mechanisms and lifting techniques.

Wider support networks

Four people said they would like a larger support network or more back up contacts for emergency advice. Two carers specified that they would appreciate more respect for their role from service providers and employers: *'I've never asked my employer for anything before but I need compressed hours -they should understand'* and *'Who cares for the carer? Really it's nobody.'*

Long-term care plans

Three family carers stressed that a long term solution had to be found for their relative's care needs. *'For now, my family are supporting me to be a carer - I keep telling social services that my role is temporary but they take no notice.'* Two people told us that a care home would be the best answer but costs were a barrier.

Broader societal awareness

Four people felt there was a need for a broader societal understanding of dementia so that friends and services could feel confident to support people with the condition. One person suggested monthly family sessions at Streatham Dementia Club could help build family understanding: *'It's good for children to understand and feel confident to cope, for example with grandparents not knowing their names.'*



Summary analysis and recommendations

The Dementia Action Alliance has produced a series of seven outcomes which people living with dementia aspire to². They include having personal choice over decisions and having services designed around their family's needs.

During our investigation, we have gathered experiences of a range of services and, while there have been some noticeable positives - the older persons units and rapid response service in particular - our general impression is that bureaucracy and over-stretched public services are hindering opportunities to deliver the person-centred care that the Alliance's outcomes call for.

The frustrations expressed by most of the carers we spoke to often seem to hinge on delays and difficulties in making contact with key agencies, combined with a lack of dementia awareness amongst the professions - from district nurse teams to domiciliary carers. The flexibility required for successful person-centred approaches also appears to be absent from many of the support arrangements proffered to the carers we spoke to.

While personal budgets may well help to offer scope for families to shape support to their particular needs and preferences, roll out of this model will need to be carefully monitored and assessed to ensure it is manageable for service users and delivers what it promises for them.

The current combination of rigidity, delay and lack of understanding is, in our view, putting unacceptable pressure on a cohort of people already giving so much to support their relative in difficult circumstances.

The Alliance's outcomes also include having an enabling and supportive environment, along with a sense of belonging within the community. Given that human contact for people with dementia in the form of respite cover was identified as the biggest need by our interviewees, befriending schemes and other face to face contact would seem to be a particularly valuable investment for supporting the wellbeing of both carers and their relatives.

We recognise the challenges in tackling these unwieldy systemic issues, particularly in light of continued budgetary pressures. However, below we suggest some steps for consideration.

² DAA outcomes: <http://www.dementiaaction.org.uk/nationaldementiadeclaration>



Recommendations

Recommendation 1

Lambeth Council and NHS Lambeth Clinical Commissioning Group (CCG) should identify an appropriate way to review how key supplies and equipment can be delivered more rapidly to service users, for example, by charging a community multi-disciplinary team to identify solutions.

Recommendation 2

The memory service and Lambeth Council should ensure that people with dementia and their family carers receive care assessments promptly after diagnosis, and are allocated a Care Coordinator for the rest of their lives, as recommended by the NHS London Dementia Strategic Clinical Network's guidance on immediate post diagnosis support³. This should also apply to people who have already received a diagnosis and their carers.

Recommendation 3

Lambeth Council should ensure that self-funders are readily offered advice on care options, in line with the Care Act 2014.

Recommendation 4

The Health and Wellbeing Board should ensure that dementia is addressed holistically in its strategy and commit to developing a borough wide plan to make Lambeth dementia friendly. This should include drawing on best practice insights from the Health Innovation Network's dementia programme and the identification of a body to lead on the initiative, such as the Ageing Well Partnership.

Recommendation 5

Following the CCG's lead, Lambeth Council should consider making a commitment for all its employees to take part in the 30 minute briefing session to become a Dementia Friend. Adult Social Care service teams should be prioritised.

Recommendation 6

Commissioners should ensure that successful dementia clubs and carer support services - such as those featured in this report - have the resources to continue their work in response to demand. Consideration should also be given to investing in volunteer befriending schemes specifically for people with dementia including those at more advanced stages of the condition, which would have the additional benefit of respite for family carers.

³ NHS London guidance: <http://www.londonscn.nhs.uk/publication/dementia-immediate-post-diagnosis-support-guidance/>



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