

# ‘Care for me at Home’

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## **An audio and visual exhibition based on narratives with individuals who receive Home Care in the London Borough of Bexley**

### **Interviews**

This exhibition is based on the findings of a Domiciliary (Home) Care research study undertaken by Healthwatch Bexley, and academics from the University of Kent and Christ Church University, Canterbury. Commissioned by the London Borough of Bexley, a total of 26 individual interviews with ages ranging from 55 years to 102 years were undertaken in Bexley between May and September 2015. All interviews followed a life story method where individuals were encouraged to freely discuss issues they felt were important to them.

Users of Home Care were found on average to be generally ‘very satisfied or satisfied’ with the home care service. However, the more in-depth research approach elicited more complex responses with the majority highlighting some concerns about the service, most commonly around inflexibility, unreliable staffing and the frequency and duration of visits by care workers. Improved communication and continuity of care were indicated as areas meriting particular attention. Generally, recipients of care were more satisfied with the service than family carers with an active caring role, who were more likely to express criticism.

Positive responses and praise for care workers were linked to when a positive relationship had been enabled by consistency of carer and empathic interactions. Recipients of care valued friendliness, empathy, individual care, humour, experience and dedication. For many respondents, care worker visits were the only regular human contact they received and consequently felt, when done well, the contact enhanced their quality of life. Lack of consistency of care worker, attitude of care worker, or language barriers were cited as reasons for not benefitting from a positive relationship with care workers.

Experiences of pathways and degree of choice over care options were mixed. Greater involvement in care planning was cited consistently as a means of improving the service. Particular issues that needed addressing were lateness, inconsistency and inconvenient care schedules which disrupted daily plans and expectations. The negative impact on recipient’s quality of life included missing social activities, not having sustenance or help with toileting/changing incontinence pads when needed; or not having other needs met due to shortened visits.

Unmet care needs were most frequently identified in the areas of social support (isolation and loneliness) and participants talked about the benefits of, and improved quality of life from individual one-to-one sessions, having a warm meal or engaging in particular activities. Whilst some recipients identified their Home Care as providing a break from isolation, for others, loneliness was seemingly reinforced by care workers who did not engage with them, or were seen to lack warmth.

The main areas care recipients cited for improvements were time-keeping/scheduling and quality and scope of care. Some participants stated that they felt there were no improvements to be made, while others were ambiguous in their response.

### **Photographs**

Photographs were taken of the participants in their homes.

### **Exhibition**

We are delighted to be able to share extracts from the archive with you. These are arranged around the themes that emerged during the study. Though we can only show a small number of extracts here, those displayed offer an insight into the important narrative collection we have started to build.

Oral history enables individuals to tell their own unique story in their own words: all written words and voices from here on are those of the participants.



# Home Care: changing realities

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Well if I didn't have the care I wouldn't be able to do the things I do.

I need care all the time. I hate being like this because I've always been a very active woman and I worked 'til I was 60. I used to keep the house and the garden clean and things like that and then suddenly when something strikes you down and you can't do it, it's suddenly hard to bear. In the beginning it's very frustrating and very tearful about the fact that you've got to have someone to do something for you but I'm lucky that I do get someone to care for me.

I wouldn't be in there partaking quizzing or go down for anything or even go down to chat if I didn't have the care because I can't dress myself. I'd be in my night clothes all day long or be frustrated which is not good is it.

In the morning I have a carer that helps me, because I hoist myself but she helps me in the bathroom and getting dressed and washing up a few things, makes me a cup of tea and a bit of breakfast. In the afternoon carer does the washing up for me, makes me a cup of tea and does whatever, makes me a sandwich or a bit of food and what not.

As I say, I couldn't manage without it and I'm so lucky to have it otherwise I would have to have gone in to a home of some sort. In a few years I will have to be looking at the homes.

It [Home Care] makes me feel safe to stay at home and I can keep my dignity, not having to feel defeated, like I've given up.

Well I feel very fortunate, I feel very fortunate to have such good care (becomes tearful). I couldn't manage without; I would have to have gone into a home because I can't stand at all.

## Transitions: 'home' as a changing space – adaptations, the first step

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I know things have changed and I can't do the stairs anymore and then there's a seat in the shower, ha ha (laughs), but I know all the sounds and feel of everywhere, I know where I keep things and I have so many memories, I can't imagine not being here.

Because that's what I miss most of all, walking round in my own home and doing things I used to do because I always used to get my own breakfast, get myself up and washed and lunch, I miss doing that for myself. I miss looking out at the garden because I can't see that now. We've got a lovely big fish pond and I can't see that.

I'm not able to get up and walk around and I can't walk without using that even I walk up and down the hall about 6 times a day I try to do it but because I think I need some exercise and I can't go out unless somebody takes me out. That's the only thing about this house, it's not wide enough for a wheelchair so they have to take me round the back and bring me in the kitchen door.

I love it, it means I can still be here, it's still mine, I needed to get used to it, the changes, but I'm not stuck any more, I don't have to worry.

I used to but I find it difficult now because my shoulders so painful. I've got a big wheelchair but it's too heavy. I've got two friends who are obviously my age so they not very strong and couldn't lift a heavy wheelchair, but the girls have bought me one for Christmas which I haven't got yet. It's a light weight one and my friend said she would take me over to Bexleyheath shopping in it. If I can get in the wheelchair and she can lift the wheelchair into her boot, she can't the one I've got at the moment it's too heavy. I'm hoping that I'll be able to get out a little bit more.



## ‘Home’: no longer a private space – conflicting feelings

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Sometimes they leave the kitchen in a terrible state; they leave all the stuff in the sink, not washed.

Oh yes the carpets a filthy state through the carers I’m afraid. They were going to replace it but they took two years and they never replaced.

They are often in such a rush, they can get impatient. They even threaten to leave me half naked in the bathroom and I said you can’t leave me like this half naked because I couldn’t dress or dry myself.

I was breast fed and I have seen more of mother’s naked body in the last 18 months than ever before. She’s had her private parts seen by more strange men than ever before but I often come in and find that they’ve left her immediate part covered up by something or other. But they often do lay her completely naked when I’m coming in. But there are men about in this business.

I wouldn’t say it to them necessarily but I would know straight away that I don’t feel safe, I wouldn’t feel safe. Yeah I would then say that I won’t have a bath to them and that’s to my detriment. That day I would probably have a few more hurts in my body than I would like although I do have pain patches on me.

She was very embarrassed right at the very beginning with somebody washing her down. She was very embarrassed but she’s fine with them now, she’s got used to them coming in.

When they take her into the bathroom to wash her and that, they seem a little reluctant to do it. I don’t whether they are embarrassed or what but I don’t feel that she gets a good a clean in the morning which I think is the essential time for it all, as she should do but that’s the rarity.

# The organisation of Home Care choice: the next step – influence on type and level of care

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Nobody rung us to warn us that it was happening, so this girl turns up and we didn't know who she was.

She never feels safe. We've had to take all the locks off of the doors because she was locking herself in and the carers couldn't get in, I couldn't get in. So we've had to take those off the doors and take her keys away as well because she was locking the door so we took the keys away but they are still here somewhere.

They basically put a plan in and you sort of pick and choose what is more beneficial to you. So yeah you have full say on what you require sort of thing.

We didn't have a say really, they just told us what we were having, suppose I just thought they maybe knew best.

Social services in hospital were absolutely atrocious... they were totally incompetent, you could never contact them. I think the other thing that I found was all the questions were driven financially and I totally understand the way things are at the moment with cut backs, but everything was 'do you own your own house', 'how much savings have you got's and those are the initial questions it was not about what are mum's requirements.

They contacted Bexley Brokerage which I thought was a laugh. They are telling us who we are going to have and we are paying for it.

I just chose [company] because I liked the name. Anyway since then I've had them and I haven't changed them or anything even though I don't often agree with them.

I was told that it was policy from Bexley council that we could not stick with the same company that it had to be changed. That's why I had to move from [company A] to [company B] which was a bit – once we got used to one set of carers coming in, we had to start again with another set.

Initially the council just sent an agency yes. That agency dealt with me for some months and then, I wasn't really happy with some issue with them and I changed to the one I have now.

Well they told me what time they thought I could manage with and that's all they stick with. I think, they are very good; they will listen if I phone up. I don't complain any more than I can help because I know they do their best.

I said that I didn't feel that 15 minutes was sufficient time and I was told that was all that was available and that could be provided.

# Logistical implications: timings and lateness

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So a couple of times they've come and I've said it's too early, I'm not a toddler but you've got to be with them, work with them because they've got their list to do.

There's nothing I can depend on and indeed, my life is on hold because you were coming this afternoon I dashed round [...] this morning to the pharmacy, I had something like a short hour to get a prescription picked up.

Oh yes, I'm very satisfied with [the company]. The only question I had about it is when I first came out I was priority so I got an early appointment for breakfast and then since November it's been getting later and later and sometimes it's half past nine, quarter to ten, that doesn't suit me because I sometime have people coming in to see me at ten o'clock and I'm not ready.

I do object when somebody comes here at half past five to get you undressed ready for bed especially in the summer. Someone calls anytime between 8 and 9 o'clock which is quite nice for me.

Weekends are murder, you know on the weekends that they are going to be late whoever, because they would have had five or six people go off sick every weekend.

Morning and evening they are the same carers. Weekends, it could be anybody and it can be anytime which is very very annoying at times.

We do not have allocated times. Sometimes they will come and in and I've said to them 'Well you're late compared to other times' and you realise, we are slowly realising that they get here when they get here and they sometimes get extra people in their round so they're even later. We've never been given a specific time actually.

Sometimes they were two hours late, sometimes they were two hours early. One day, a couple of occasions no body turned up at all to put her to bed and she had to spend the night in the chair all night. Other times she was just left for 10 hours a day because of the first one being early and then the second visit being late and the one in the middle being missed so it wasn't sufficient no.

The other day I didn't get the morning call until 11.30 and of course during that time, I can't get out to make a cup of tea or anything so... and I'd drunk all my water that they left me the night before.

[Company] could be better if the person can't come within an hour of the time they've got on their sheet they should ring up and say 'I'm sorry Mr H I can't get there 'til so and so, do you want me to cancel' and I'd say yes and get myself ready. So it's just a bit of communication but nothing improves in that manner.

I get upset, I look forward to going to church and seeing people and being part of it again, I would go every week but with the carers changing times it's not possible.



## Tolerance and empathy for workers and providers

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Now this young lady today she, just for an instance, she lives in Greenhithe, she had been to Crockenhill before she came here and after she had done me she had got to go back to Crockenhill ah... doing lunches and of course she was very late, I mean I rang this morning and said 'well is anyone coming this morning to help me'. [...] I said to the office here, I said, 'If you, if you had to pay petrol money, I said you would be getting your finger out and sorting out all these things'.

We did have another agency, but there's been a couple of agencies erm and it was difficult cos the last agency that I used erm that hadn't got cars so they used public transport and it was really difficult to, you know, they'd be coming at all hour really and er I think the level of care was not good at all. [...] This [care company] is very good, they have cars so they, they can more or less say what time they are gonna get here and that's very reassuring.

The weekend is bad, when I say bad it's because their times are mixed up and you might not get them until 8 o'clock, not their fault that's their list and they have to follow what they're doing.

If they get held up then you've got to understand that the traffic's bad or things have happened to them.

You can't really fault that because they've all got to have their staff turnover so that's the only quibble I've really got which isn't one really is it, it's the way of the world, people need their jobs [...] that doesn't happen a lot so yeh no worries.

I'm so happy with the actual care we are getting that, yeh it would be nice but I can understand why they can't always provide regular carers. And as I say as an individual you might get a bit uptight about it but then again you've got to be fair, a lot of people probably want the same sort of care, are on at the office just the same.





## Lack of consistency: carer regularity

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She said to me that she couldn't build up a relationship with carers because she was seeing different people all the time and she didn't know who was coming in and out of the house.

I see so many people and I can remember everybody's name. I'm alright with some, some I get a muddled up a bit. I get, because I said I like consistency, now I have two young women who come to me Monday to Friday, they come every morning and I'm very pleased with them and got very friendly with them now. They are very good, very caring and they're observant of different things.

It's a bit awkward really. I do have what they would call a regular carer but then she's never available on a Wednesday, she's not available weekends so I have another carer for the weekend, usually regular but I think they are going through a bad patch because at the moment, anybody seems to be coming. They are being let down by staff going off sick, I think they are short of staff in some respects

They [company] are very good but when they have to fill in with somebody that doesn't know the area or doesn't know me it's awkward for them, new person coming in so I can understand it's not very pleasant for them. I dread it.

In the winter when a lot of them get colds and that and stay at home, don't work obviously and the.... This particular weekend I had six different carers on that Saturday and Sunday and every other day of the week I had either two or three carers. I've never had a complete week with just one carer.

I'm still at this stage, the only one I can say I've got as a regular carer now is my morning carer. But that's only been in the last year that I can actually think she's my regular carer. Otherwise they just turn up, you know and that's not satisfactory, they just turn up anybody.

I've had carers that don't really know what to do because they don't know my kitchen, they don't know the hoist, but I know the hoist so I can tell them what to do, how to hook it up.

It really is a battle just trying and all we want is a decent carer, continuity and reliability.

Obviously continuity of care for someone who is visually impaired is really quite crucial isn't it. When you don't know who you are letting in through that door and that voice changes on a regular basis.

I've seen so many that's come and that they have got it in them to be good carers but because of like I find you keep getting different one, I find they get pulled down by being sent from pillar to post from one to another. They're not able to get to know anybody properly before they are given a round.



## The caring relationship: positive carer interactions

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Some of them, they'll come in and they'll say 'oh you're upset [name] what's upset you, come on now', so they come over and get hold of your hand and ask me to tell them (laughs). It's quite comforting, absolutely.

[Carer] reads all what the other carers say and if she notices they're not doing she will put a note in the book. ... She's right on top of things, she's very, very good. I think she's done that job for years and enjoys it I think as well.

They're friendly, they're sociable, they're like a breath of fresh air when they come in because.... Ooh they're all getting married at the moment and getting engaged and having babies. It's lovely, they're lovely girls.

There's always laughter going on, I'm down stairs and I can hear them laughing up here so that's what you like to hear isn't it.

I keep on saying it, it's the older carers that you get and that's very nice and very good and I really must, I can't say enough on their behalf because they are so so kind they really are kind.

Well there's skills in their own personalities and the interaction between us, that quality, you know the caring part of caring is very important as important as what they are doing physically for you. The fact that they do care about you is more important or as important as what they have to do physically.

Yes they do wash me intimately they say 'should we do that, can we do that'. I'm alright now but the first time I was very embarrassed it was terrible especially things like intimate, if I want to go to the toilet. I used stop and hold up because I was embarrassed and so nervous, it's much better if you know and like them, if you're used to each other.

She's lovely, she really is. She's like my friend, she's like my sister. I've got four sisters and they don't care for me like she does, I'm very lucky. She makes me feel good about myself.

## Professional distance: the absence of close carer relationships

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The neighbour said that she got a marvellous relationship going with her women. I said 'no I just can't, I don't want to'. [...] At Christmas I didn't buy them presents or chocolates or give them a drink or offer them a drink, I've never offered a cup of tea and I will say thank you or goodbye and they always reward me by leaving both doors wide open.

Well you speak to them, very loosely, the same as I'm speaking to you. They're strange people coming in your house but I can talk to them and get a reception as such, they're that good. It's not like a friendship or anything.

Well they don't get long so you could converse with them, yeh really, I'm not one for bleeding out, bleeding my heart out to them so yeh you can have conversations with them and I get on well with them so yeh they're okay.

## Cultural expectations: communicating need

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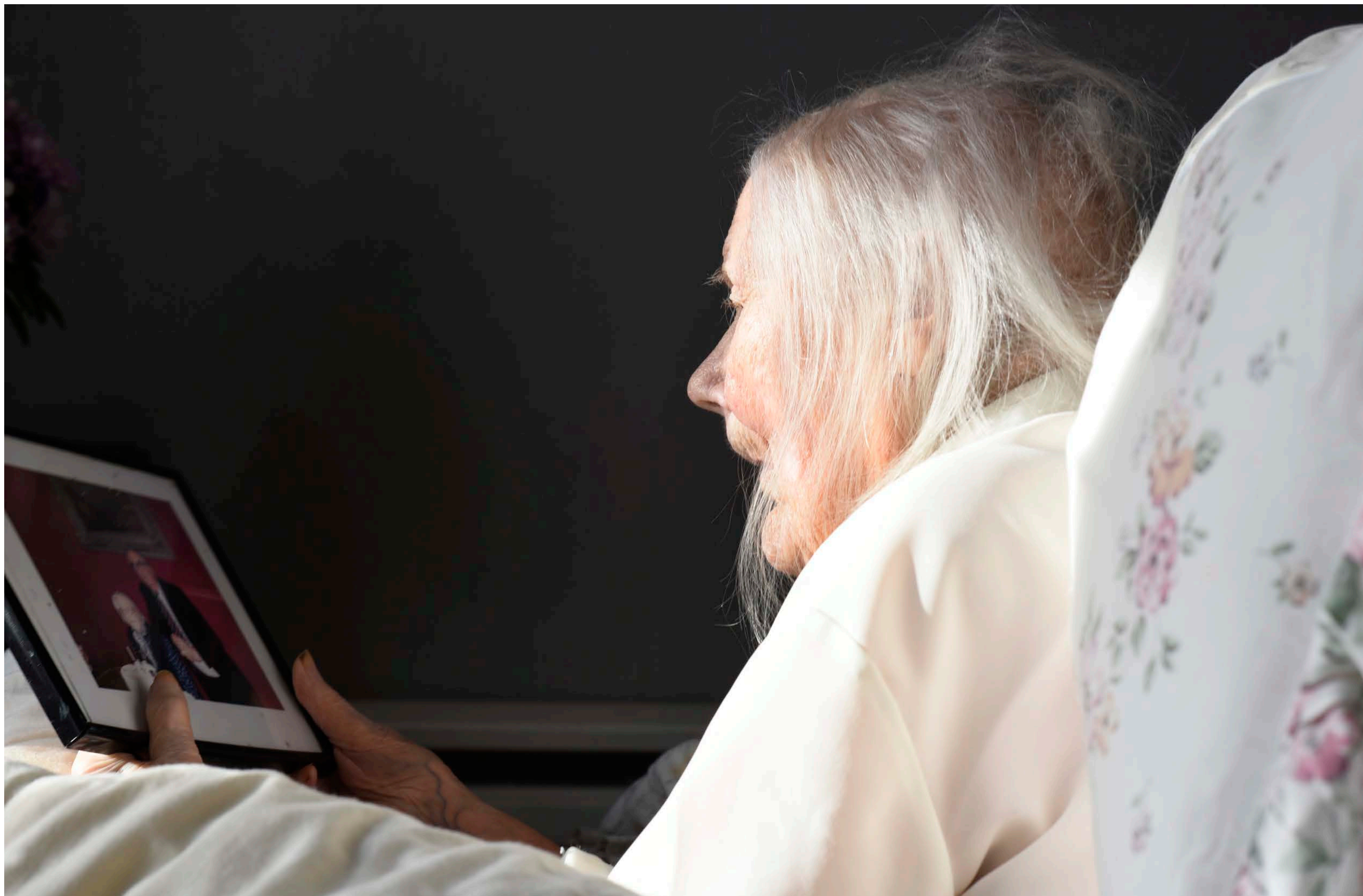
They were coming in also speaking in their own language in front of my mum all the time. I used to pull them up downstairs if they done it in front of me and would say 'while you're in this house you speak English, if you can't speak English then you don't speak'.

They might send someone who doesn't speak very good English, or someone who is a bit slow to understand, who you have to tell them what you require. I'm trying to explain to them what I need, it can be a bit monotonous.

[Would like to have] just time to talk really, I don't know if would help with my present carer because we wouldn't be able to have much of a conversation I don't think.

She was a lovely girl from Uganda I think but as she said there aren't any jobs out there for actors and actresses so she was doing this. I said 'do you like it' and she said 'I love it I meet lots of people' and you could tell she did love it, the way she treated you and that and she said can I make you a cup of tea before I go, I said no it was alright. It's just the difference you get. I would ask her about her life at home, it's very different but different can be good.

No they've always been very nice. Whatever nationality they are and you do get different nationalities, I mean I can understand some of them but they are there and they do give you the care that you need. I've got no complaints about the care I get.



## Lack of training, stress and pressure: barriers to good care

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Sometimes I may get a carer here that's very heavily pregnant and they can't dry me and I know they are hurting and I'm hurting to see them hurting, very frustrating.

I know they haven't [been trained] because I've had so many who's admitted to the fact that they haven't had really any training, they've only been in the job a matter of a couple of week and this sort of thing and they haven't had any care experience before they join this company.

I couldn't believe it, three times it was, three kettles burned and melted, they were the cordless type so I suppose they didn't know, but three times!

That's another thing the old carers are well trained they go on courses and keep the training up as well but I'm afraid they don't get the training the old carers used to receive. The new carers coming along, I don't think they even shadow them now, they were shadowing others to get trained but I don't think they are even doing that now. I don't know what training they get if any, it's very poor – the new ones.

One came round that was heavily pregnant, had trouble moving my mum because although she was only four stone naturally because she hasn't got the use of her legs now, you do have to lift her out of the chair and things, and she couldn't manage on her own. Some [carers] were better than others.

Some of them are very strong on being here for half an hour and I know they are standing about gossiping and they haven't started on time and somebody said to me 'oh well they are making a relationship with the patient', 'No they're not, they're outside in the hall gossiping and talking about hair styles.

I mean they might be in the middle of dealing with a client and their phone goes off and it's the office phoning and asking if they can take another one and quite often the carer will say 'well I've still got eight more to do, as it is I'm not going to finish until 11pm tonight.

I think it's more about the system than about the individuals because the carers that come in are under an enormous amount of pressure because they are given really rigid schedules to stick to and they have to be in and out in 15 minutes and they know literally that's what they can spend.

## Unmet needs: loneliness and isolation, facilitating community involvement and independence

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I've lived here now for 49 years and none of these people who live around me apart from that man next door who I rarely see and a lady this side, I don't know anyone else. Several of them have died or moved away. The lady and the man next door are in their seventies anyway and having their health problems and I certainly wouldn't add to them so I don't even think about calling on them, do you see, I won't do that.

When mum first came out she actually required two carers and the girls would come round and talk amongst themselves, they wouldn't talk to mum.

It's the loneliness, that's the only thing that we can't do anything about. We can't be here all day every day. [Family member]

I do find that I get very depressed, I sometimes don't see anybody all day. They have been trying to get me into a day centre but I've been waiting about a year for it.

I am more or less limited to just sitting in this chair really.

They're not, it doesn't seem to be part of their instructions that it would be nice if there was some camaraderie between them and I had one that didn't talk all the time that she was here.

It helps me stay in my home but doesn't help me do what I want to do. Health wise it won't let me. Well I'd like to be able to get out to the day centre, give that a try and just meet people.

## Transport issues: feeling trapped or isolated

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I manage to muddle through on my own to be honest. My main issue really is transport which isn't helping me live but it's getting from A to B that's the main stumbling block at the moment, I'm sort of trapped.

No I'd like to go to the theatre sometimes, you know perhaps to the Orchard and erm, but even if I got a taxi I've still got to get out and it's a bit tricky.

I used to be [religious] more than I am now I can't get out. I used to go to church regularly up to probably four or five years ago. I find it difficult to get there now so.... It's gone by the board a bit and they haven't taken much interest in me, no one seems to care very much if I get out or no.



# Feedback and complaints

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If you don't make a fuss they won't bother.

We had a meeting altogether, the manager of the care home didn't feel that it was important enough for her to attend and sent a deputy, the deputy was 15 minutes late and hadn't been briefed so didn't know what the meeting was about or why she was there and she didn't take any notes either and I haven't had a written reply since and that was on the 17th February.

No, the manager was coming but she hasn't. She said she'd ring me up and say that she would come and talk to me but she hasn't come so I'm just waiting for somebody because sometimes on a Sunday I've had to ring up and ask when is the carer coming because it's got later and later because I have a different one on Sundays. Then she did say well I will come and see you but they haven't come.

I've spoken to other people that belong to different companies and they have the same difficulties as I have with [care provider] so I think I'm not going to improve on what I've got so I need to make the best of it. It's not easy, only once or twice I've phoned up and said 'I've been up since 5.30 this morning and it's now quite late, I haven't had a carer come to me at all this morning. I do understand that you're probably busy with one thing and another but this is a person at this end not part of the machinery'.

But as I say, it's, I can't have any more time, that's what the council have said so really it doesn't matter what they say or I say, the council said I can just have the hour in the morning and the hour in the evening that's it.

Of course as I say to me 45 minutes was not enough time to have a bath. Yes she took it on board, she understood what I was saying but because of the law, now whatever law she was relating to I don't know, she wasn't able to do anything about it.

Sometimes I feel so upset with them and think should I do with another firm that does it, I've have thought about it at the back of my mind. I know I can do that.

Oh yes they do [listen] because when we spoke to this lady called [...] it had some sort of repercussion effects them all I think, don't know what it was but yes she's determined to sort it out oh yes.

So they do know me, they might cringe when I call up (laughs) I don't know. It's no good sitting quietly if you've got a.... it's no good letting it pass because they think then 'oh she's easy going and won't mind'. I don't say that's how they think but I've known someone who works for [care provider] and she says that's how they think, if you don't make a fuss they won't bother.



## Care recipient recommendations

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They have not been into this house to assess it for their staff and they should be here assessing the whole place for their own staff as well as for... and to know me as a person and not just a name on a page.

Fair and regular times for visits. It would be ideal if they could really stick to a timetable.

Time keeping is really the only one.

Just the time they come and the quality of care when he comes and they're all good.

Regular carers that you have that you can engage with that definitely not just any carer but someone that understands you being visually impaired and can chat away.

Just time to talk really.

I just need more time, it's always such a rush, it puts you on edge, they need to allow more time.

Nothing's perfect but [care provider] is as good as it could be if the office staff were improved and all the carers that come got the proper training like they used to have but they don't get now.

They're all individuals so these people they employ need individual training.

Only as I say I feel that.... [care recipient] was always an active person, cycling, swimming every week, but she's not doing anything. She should, I think, be doing something. [Family member]

I think it could be improved by being more joined up with GP's, hospital, district nurses and I think it could be.... At the moment it just seems that it's all about the money and just having rather than the care just getting in, getting out and doing the bare minimum when it's people's lives you're dealing with here. Giving people the option that if they have got funds to pay more and to get a better service that they can do that as well and have some choices. [Family member]





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Research Lead and Author: Dr David Palmer

Research Team: Dr Lucy Williams, Prof Eleni Hatzidimitriadou, Rosa Hossain, Claire Ball, Nicola Rigby, Lotta Hackett and Anne Hinds Murray

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**For further details contact**

Healthwatch Bexley

<http://www.healthwatchbexley.co.uk>

or on: 020 8304 9344



