Healthwatch Hammersmith & Fulham – Carers Project

Part 2 - Case studies

healthwatch
Hammersmith
and Fulham

Introduction

One to One Interviews

- 9 structured interviews were conducted with carers, over the phone, online or face-to-face.

- Questions included:
    - When did you first identify as a carer?
    - What kind of help would be most useful to help you maintain or improve your physical/ mental health and wellbeing?
    - As a carer, have you ever struggled to afford basic health care services, such as dental or eye care appointments, or prescription medication?
    - What would help improve your life?

- The interviews were recorded and transcribed and comments from these conversations have formed the quotes and case studies included in this report.
- This report should be read alongside our main Carers Project Report, which can be found on our website.

Key Findings

Identifying as a carer does not come easily. It is a gradual process, often taking years

Information and materials about recognising/being a carer can be better shared and promoted via GP surgeries and websites

Carers are exhausted, physically and mentally. Treatments, massages, counselling, as well as organised exercise and cultural activities would greatly support carers health and wellbeing.

Practical solutions allowing joint/coordinated GP appointments for carer and cared for would support carers health better.

Respite care/breaks have a huge positive impact for carers and can be the difference between survival and breakdown.

Identifying as a Carer

Quotes

“I didn't really, I've been **looking after my mum for 11 and a half years, but I didn't register**. […] mum didn't get diagnosed for about seven and a half years. And in that time I didn't really recognize myself as a carer at all. I think that's a problem a lot of carers have. […] **I think really carers don't understand the difference at the beginning**.”

“**It sort of creeps up on you**. […] I started by doing all the admin, all the shopping, all the cooking and so on and **then I sort of realised** that yes that’s what I’m doing now. I am caring for another person and not just as a husband-and-wife cooperative thing.”

“You don’t realise that you’re a carer initially […]. As he [husband] became more dependent on me I realised that **I wasn’t able to do what I wanted to do when I wanted to do it** because the caring was taking over.”

Audio clip
Transcript below

"Well, I have been a carer for now 22 years, 14 years of which full time and I certainly didn't see myself at all, as a carer, I was just a daughter, and a wife, who had well, I've, I've had a disabled mother for a while my mother has been in a wheelchair for a great deal of my childhood. So I knew, I suppose looking back, you know, I would have been, I suppose I would have been a young carer as well. But I certainly didn't identify as one. And it wasn't actually until I realised that not only did I have to give up my employment, but caring became sort of an overwhelming well, it consumed my life. Basically, it became, it had to become full time as I say, I had worked before."

Sharing information on being a carer and the carers assessment

Quotes

“Through GPs, through the hospital.”

“If it was easily available on a **website** or maybe displayed in a GP surgery or something.”

“Through GP practices. I think that **one of the issues in Hammersmith and Fulham** - and probably in many other areas - is that **there isn’t enough communication**”

“A woman called me and identified herself as being like a social worker and she kept in touch with me for 8 weeks. […] She was just full of information, but she said that her job was being **phased out**.”

“No, I **didn’t know** there was any such thing [carers assessment].”

“Through the **Carers Network**, they arranged it [carers assessment] for me they were **very good**.”

“I think the most important thing for carers in general is to have **clear pathways for gaining support that you’re entitled to**. And there are different streams of support. It’s not entirely plain sailing and I can manage to read it and work my through it but I’ve needed support with that.”

“A woman called me and identified herself as being like a social worker and she kept in touch with me for probably 8 weeks. […] **She was just full of information**, but she said that her job was being phased out and she didn't know who was going to carry the baton going forward.”

Help and support to maintain/improve physical and mental health and wellbeing

Quotes

“Caring has a really big physical impact on you. The worst is the tiredness and the back problems.”

“Service like podiatry”

“Mental support and social support.”

“If I could have the ability not to have to decide whether or not I can fill my prescriptions, I'm not even seeking my prescriptions anymore. […] I can't afford it. […] **Flexibility when you schedule appointments** so that you might be able to get an appointment if you need one alongside your cared-for. […] I have scoliosis, which is exacerbated because I'm having to lift a person who is three times my weight How about us having access to fitness classes or deep tissue massage or even physiotherapy treatments?”

“We had with the **Carer network** a few very interesting **Zoom calls** during the pandemic. Like for example one was from Windsor Castle, one was from the Chelsea Garden. We also got this ticket to a **museum** which was really amazing because those two hours I could just completely forget about [caring] and it really helped. So maybe more of [those] kind of activities.”

“I don’t want to appear as a victim, but it is difficult to cope with mentally. It would be nice **to talk to someone from some kind of counselling service** occasionally.”

“Just having space, you know, just, just the **respite, a breathing space** does wonders for the mental health because you are drained, you're drained physically and you're drained emotionally because there is no break, you know, you don't clock off. So having **adequate counselling** would help that you don't have to be on a wait list forever.”

“In the hospital [there] was a **psychologist**. They changed quite often, so we didn't see the same person very often. But if I'm honest, if I think back to that, I think in a way it was almost too early because I had no idea what lay ahead.”

Audio clip
Transcript below

“I don't get any of the exercise that I used to get. I'm **exhausted** because I'm helping a man who's six foot five in and out of baths and showers and everything else. I'm **tired**, but **I no longer do anything for me in terms of organised exercise or mental stimulation**. And I don't see any way around that.”

Support on education and wider opportunities…

“**The chance to go into the uni**. The biggest issue is we pay to the agency which does not really do a good job, I do all the jobs and I don’t get paid.” – Carer A

“If there was **subsidised access to classes** that could enable carers like me to actually attend a few sessions or classes a year then that that would make a big difference.” – Carer J

Respite care and breaks

Quotes

“For people who have kids even to get a **place full-time in the nursery** would be great. I didn’t have a chance to use that.”

“I’ve ended up doing a lot of night working and not getting enough sleep. That’s when I started getting **carers to come in during the day so that I could do some work** during the day and I had someone to help him to keep himself busy because really he can’t take any initiative to do anything… Whatever suits the person that you’re caring for but these carers who have expertise in dementia can be very patient and therefore very helpful for you to give you a break.” – Carer E

“Through an organisation called **Headway** my husband registered to do something on every Tuesday for six weeks to meet with other people who had suffered a brain injury. And that was great, both for his self-confidence and for me, because it meant on a Tuesday morning he would go out [...] and I had a couple of hours even just to do things in the house that I don't get to do normally.”

“I think more access to **respite** for carers. I think the problem with carers is they feel very defensive. I think, I think physical effort and lack of sleep really takes its toll on a person, especially your confidence and knocks your confidence. And a lot of carers that I know, they just they lack confidence and they underplay what they do. I think rather than making them think that they're asking for the earth, sort of normalising it and **rather than making carers** have to ask for it, **offering it to carers**.”

Financial support for health care

Video clip, transcript embedded

Quotes

“I can’t afford dental service […] even [though] I need to go but I understand that it’s too expensive for me.”

“I am helped by carrying on working so we are able to afford it.”

“That is the biggest problem, actually. Dental and eye care and the prescriptions for me personally […]. It's a struggle. There was absolutely no way I could afford them. Because I couldn't use the personal budget for glasses. So I eventually with the assistance of Carers Network applied to the Carers Trust for a grant and I was able to have glasses. I haven't been to the dentist for God knows how long, I have a lot of problems with my teeth. It's just impossible. If only, I could have… an opportunity to visit a dentist and have whatever treatment I need, free of charge, just once a year, once every five years, I would still be happy. Rather than having to go there when things are really desperate and perhaps beyond managing.”

Case studies

Case Study – "Susan"

Susan looks after her husband whose disease has worsened recently. He was diagnosed as legally blind a few months ago.

Susan doesn't know about being registered as a carer or a carer's assessment and says she hasn't really had any time to think about it. She will look into it more as she hasn't been told anything and thinks it would be good if there was more information and resources available.

She says it is a big task taking on the role of a carer. She thinks the GP system needs to be more available as it is difficult to get a doctor's consultation when herself or her husband are unwell. Booking online is hard because when she goes to book there are no appointments available. Since her husband is blind, she is responsible for booking all appointments for him as well which can be difficult.

Susan" struggles to balance her work hours with being a carer. She works in fashion which sometimes includes working late, so sometimes her husband might be waiting for her until 9.30pm.

When asked what would help to improve her quality of life, she says that if GPs were more available so she can have more reassurance, then it would lessen her anxiety. She also wants to learn more about what information and resources are available or if she is eligible for anything that could help.

Case Study – “John”

John has been looking after his wife for the last 3 and a half years but doesn’t really identify as a carer. He says he did not find Carers Assessment that useful as it only focused on his needs, but what he would find helpful is to get more support for his wife. His wife is very “head strong” and often refuses any help that she is offered. They have a carer that comes in the morning to help but other than that, John looks after his wife. John says Hammersmith & Fulham council is a good council as they pay for the carer and they are the only council in England to do that.

He feels his caring role has affected his physical health: he used to be very fit: he ran marathons, but now his caring role means he doesn’t have time and at old age it’s harder to keep fit. He says his mental health is fine: he sometimes gets tired and depressed and a bit “snappy” but that that’s just normal – “everyone gets like that sometimes”. He does occasionally “feel terrible” and thinks that he should be more “caring”.

His wife receives some financial benefits which he applied on her behalf as she said she does not need them. He finds that there are some benefits that are not necessarily directed to carers but that some carers could be entitled to, but it is difficult to find out about them as they are not promoted to carers. He thinks it would be useful for carers to have someone to talk to about which benefits they could be entitled to and how to apply for them.

John has himself also experienced some health issues: he has a prostate cancer which he needs to have an operation for, and he also had an accident with his scooter which resulted in broken ribs and a hospital stay. He says that while he was in the hospital, his daughters looked after his wife, but during this time they realised how much John is needed.

About his caring role, he does think it restricts his life: he still wants to have his own life and “not just be a carer”. The caring duties came on so suddenly - “you don’t expect it”, but he says it’s just life and you “just get on with it”.

In his free time, he rides his scooter which has helped him to meet lots of people. He gets to have time to himself, but he needs to plan things in advance to make sure someone is looking after his wife.

Case Study – “Anna”

Anna cares for her daughter who has autism and difficulties with mental health. Her daughter has just turned 18 which means that she is being transitioned from children’s services to adult social care. Anna says she has found the process very difficult.

She is not registered as a carer and says she was never informed how to do this. She has had to push to have a carers assessment now that her daughter is moving to adult social services. “I had to push that myself. It’s hard because when it’s a transition when you’re going from children’s services, I don’t think children’s services do carer assessments but in adults’ they do. So, it’s hard transitioning between the two.” She also thinks someone should have contacted her once her child turned 18 without her needing to reach out. “[…] So, from when I was a carer when she was 17 and 11 months surely automatically, I continue as a carer […]. It should automatically come, and someone should contact I shouldn’t have to be chasing services, which a lot of parents are doing.”

She says she understand there is a lack of resources in social care staff, but that the process for transitioning from children’s services to adult social care should be tighter and there should be clear pathways. She says having someone supporting with the transition and to have a mental health service for young people with learning disabilities would also be very helpful.

Anna says that she knows other parents that have experienced difficulties with transitioning who she is trying to help whilst managing her own difficulties as she has previous experience working in social care.

Anna works full time and says she is fortunate to work from home. She says it used be very difficult to balance her caring responsibilities with work and she came close to leaving work or cutting down her hours. Luckily, her daughter got into a specialist college which has helped the situation. She says the psychiatrists at CAMHS and her daughter’s social worker at Stephen Wiltshire Centre have also been very supportive.

Through word of mouth in her area, Anna has met other parent carers and they are in the process of setting up a carers’ group for young people with mental health needs.

Case Study – “David”

David looks after his friend “Travis” who he met through church. David found out that Travis, who has mild dementia, was being evicted from his home. He says that “Travis” was no longer cleaning or looking after the flat he was renting which resulted in his eviction.

Travis was temporarily placed in Holiday Inn, then moved to a place in Southall – an area where he has never been. He was then placed in a care home in Ealing where Travis was happy as the staff were nice, however, he was eventually moved to an assisted living accommodation in Hammersmith.

Travis initially had a dedicated social worker who helped him to find a place in the assisted living accommodation, but David says the case worker eventually “dropped off” because she had such a large case load. Travis has a stepbrother who lives in North England; however, David says the step brother has refused to have anything to do with Travis.

After visiting Travis a few times in the assisted living accommodation in Hammersmith, David says the staff there started contacting him regarding Travis doctor’s appointments and other things, which has led him to help Travis with practical things like buying food or things he needs for his accommodation.

Travis is 91 years old, and his dementia has deteriorated in recent years. David is worried what might happen to Travis once his dementia gets bad as he has no one. David doesn’t know who to speak to about Travis future or who will look after him. “If he gets bad. What's going to happen to him? You know who's going to look after if they say, oh, he has to leave the where he is now and he is 91 in a year or two, he has to go off to somewhere else. What, however, to council to do it. I don't know who I'd go to at the council.”

For more information

Healthwatch Hammersmith & Fulham
141-143 King Street
Hammersmith
W6 9JG

www.healthwatchhf.co.uk

t: 0203 886 0386

e: info@healthwatchhf.co.uk

@HealthwatchHF

Facebook.com/HealthwatchHF

healthwatch