healthwatch
Tower Hamlets

Experiences of Carers in Tower Hamlets

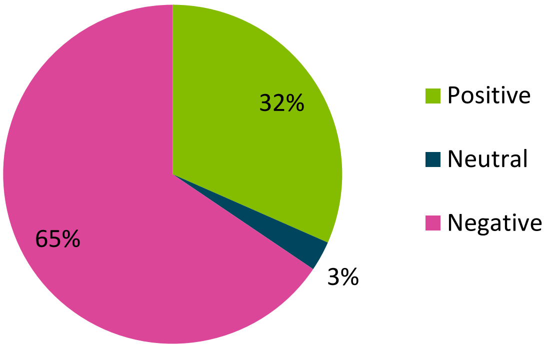
Dec 2019

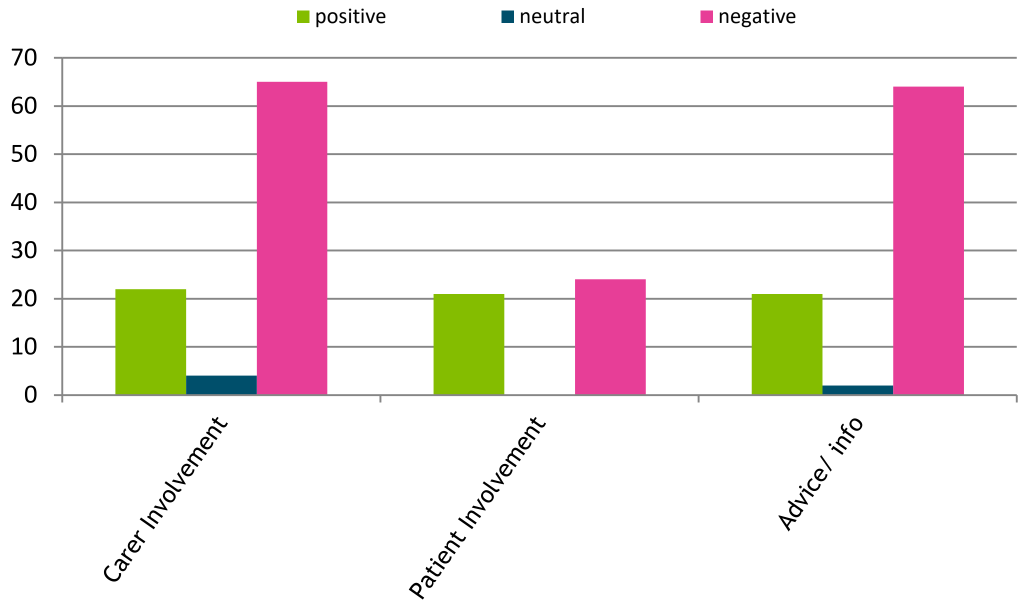
Contents

Summary

In 2018 and 2019 we heard from 187 people who looked after their loved-ones (including elderly parents, children with learning disabilities/ special needs, and family members undergoing treatment for serious long-term conditions such as cancer).[1]

Overall, their experience of health and care services has leaned negative, and they face a number of challenges:





- While opinion of *the extent to which the patients are involved in their own care* is mixed, many were dissatisfied with *the extent to which carers were involved,* and with health and social care services' poor communication with carers.
- Both in primary and hospital care, many of the carers that we heard from found that communication with medical professionals about their loved ones' health, diagnosis and needs is often poor. Many felt that they were not adequately kept up to date about their loved' one's state, but also that *the intimate*

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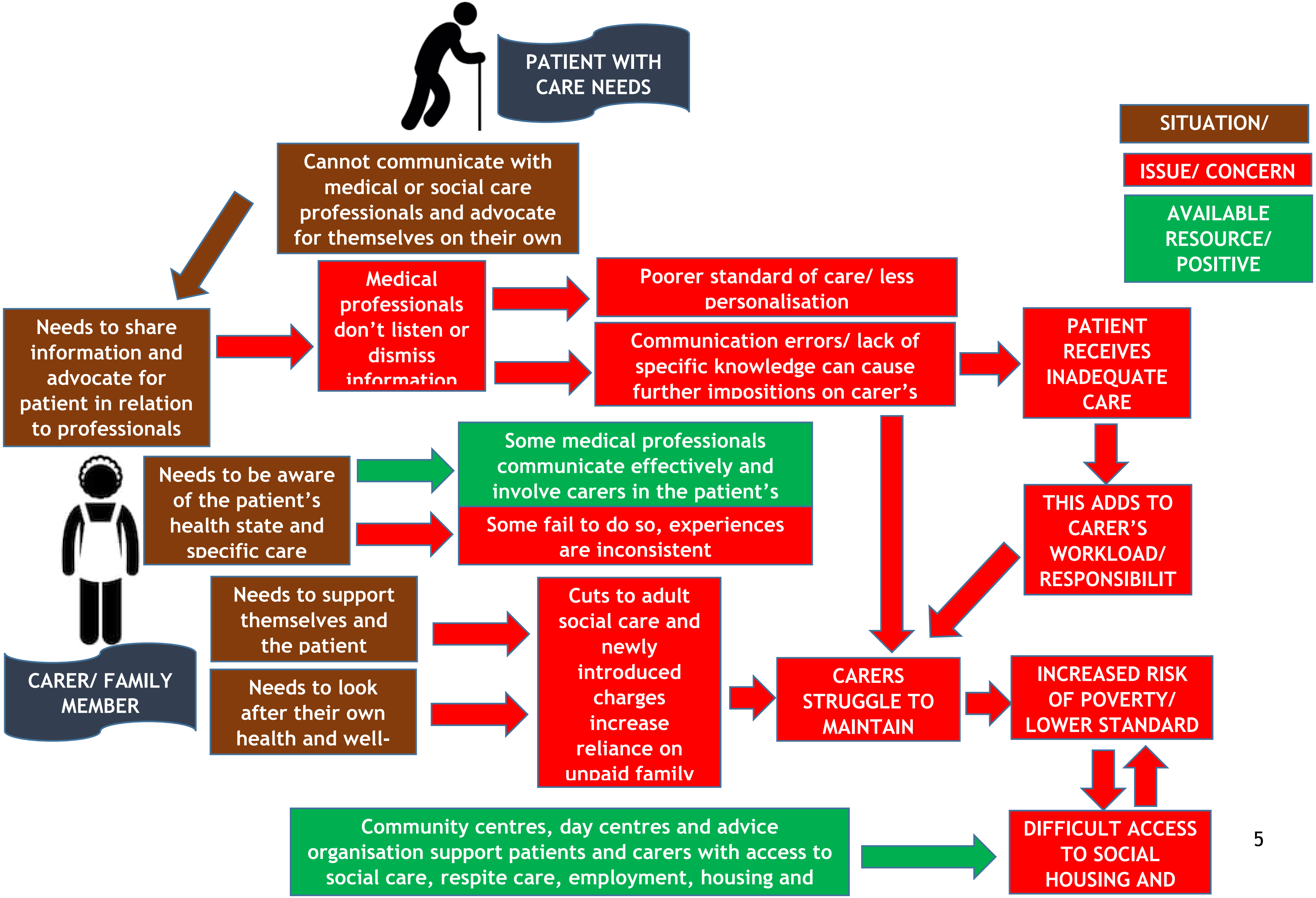
[1] Parents of children who do not have special needs or disabilities are not included in this report.

knowledge that they have about their loved ones' health and needs is ignored or under-utilised by medical professionals.

- Carers can feel under pressure to advocate for their family members in relation to health professionals. Communication and admin issues in hospitals and GP surgeries exacerbate the problem further.
- Carers who spent time in hospital alongside their loved ones who were admitted report issues including:
    - Not always being able to stay by their loved-ones' bedside, even when needed.
    - Lack of accommodation (such as beds or affordable food options) for carers who need to stay in hospital full time with their family members.
- Some carers perceived that cuts to adult social care services and NHS community services has resulted in poorer discharge packages for patients leaving hospital and increased reliance on unpaid carers. Furthermore, when domiciliary care or community healthcare is available, if the standard of care provision is poor, this has the potential of adding to, rather than alleviating, the carer's burden.
- The patients and carers that we heard from (largely during 2018) seemed to find communication with Adult Social Services poor, particularly around the cost of adult social care, charges and eligibility.
- Chronically ill or disabled patients and their carers are, as family units, at increased risk of deprivation and financial precarity. The small number of carers we spoke to felt poorly supported (by employers and by social services) to juggle caring responsibilities and employment. Consequently, while already looking after a family member unable to work, they felt like they could be forced to leave the workforce themselves, take up lower paying jobs in exchange for flexibility or reduce their hours at work.
- Accessing benefits or social housing is a daunting, complicated process for many carers.
- Community centres, advice organisations and mental health support groups are crucial resources for offering carers support and practical help.
- As NHS and social care services are forced to make continual savings and unpaid carers feel they are forced to step into the gap it is even more important that administration, information, communication systems work effectively across the integrated care pathway. Where systems don't work well carers can find it impossible maintain paid employment as they need time to navigate complex care system for their loved ones.



PATIENT WITH CARE NEEDS

SITUATION/

ISSUE/ CONCERN

AVAILABLE RESOURCE/ POSITIVE

Cannot communicate with medical or social care professionals and advocate for themselves on their own

Needs to share information and advocate for patient in relation to professionals

Medical professionals don’t listen or dismiss information

Poorer standard of care/ less personalisation

Communication errors/ lack of specific knowledge can cause further impositions on carer’s

PATIENT RECEIVES INADEQUATE CARE

THIS ADDS TO CARER’S WORKLOAD/ RESPONSIBILIT

Needs to be aware of the patient’s health state and specific care

Some medical professionals communicate effectively and involve carers in the patient’s

Some fail to do so, experiences are inconsistent

CARER/ FAMILY MEMBER

Needs to support themselves and the patient

Needs to look after their own health and well-

Cuts to adult social care and newly introduced charges increase reliance on unpaid family

CARERS STRUGGLE TO MAINTAIN

INCREASED RISK OF POVERTY/ LOWER STANDARD

DIFFICULT ACCESS TO SOCIAL HOUSING AND

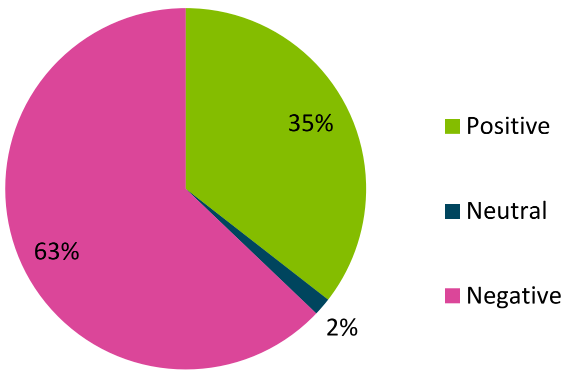
Community centres, day centres and advice organisation support patients and carers with access to social care, respite care, employment, housing and

Recommendations

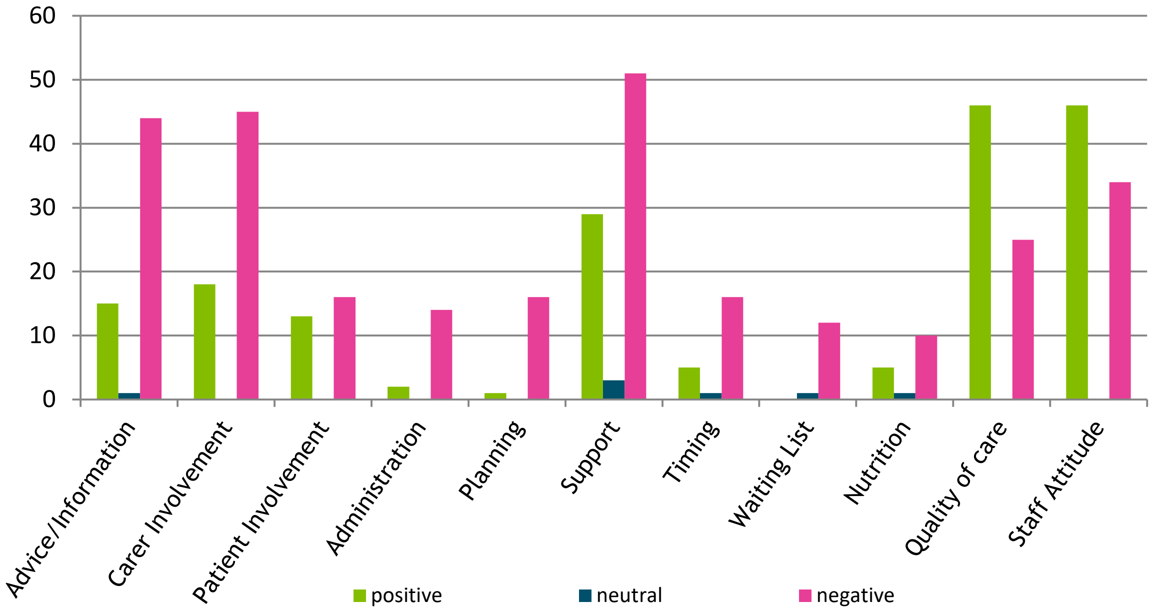
1. Medical professionals should improve communication between medical professionals and carers/ family members of patients; including clear, transparent policies on whether and under what circumstances information on patients' health can be shared with families. Improvements to digital access to services and joined up patient care plans and records should consider how carers could be given increased access to enable better co-ordination.
2. Medical professionals and social workers carrying out care assessments should specifically seek out and take into account relevant information from patients' family members on the patient's specific care needs; particularly if the patient is not in a condition to communicate on their own (e.g.: young children, learning disabilities, dementia, language barrier, acute distress.
3. Local authorities and the DWP may need to review their communication with patients and carers around the cost of social care. It is still unclear whether carers understand the policy adequately.
4. Local authorities should allocate further funding for community centres, carers' centres and advice organisations to support carers with advice and casework around access to social care, money matters, applying for social housing and benefits, employment rights and employability.
5. Employers should offer carers more flexible arrangements so that they can remain in the workforce for as long as possible.

Hospital-based care

While most carers we heard from believe that their loved-ones receive competent and compassionate care from empathetic and kind professionals, they report a poor level of involvement in their loved ones' care and poor communication with hospital staff. This leaves both them and the patients feeling unsupported. Admin and planning issues, such as delays, cancellations or errors in patient records can worsen these issues.



112 comments, 625 issues
percentages based on count of issues



Effective communication with carers and family members is highly important, providing carers with the information and the peace of mind they need.

> *My son was admitted to ICU at Royal London last week. He was critically ill and the clinical team were outstanding. We are so impressed with everyone who looked after him. It was an extremely stressful time and all of his nurses were so efficient and kind. We were always kept informed by his doctors of his progress and I can't thank everyone enough for the wonderful care my son received.*

> *My husband was diagnosed with Bowel Cancer. He needed to have an operation. The doctors*

were really good, they explained everything really well. They understood the stress and worry we were feeling and the pressures. The surgery went well, everything was good. They looked after my husband really well in ITU and HDU. He recovered well from the operation. The doctors always answered all our questions even if we did ask the same questions lots of times. Also they took the time to listen which was reassuring as it was a really stressful and scary time.

I write in praise of the whole team who looked after my family member so well. He has profound learning difficulties and functions as a 2 or 3 year old. He hates hospitals and does not like being touched by anyone who does not know him. It is difficult. He is deaf and has no speech. The whole procedure was arranged by the outstanding Dr X in restorative dentistry, and Y the lead nurse in Nutrition Support based at Whipps Cross. Each and every one of them bent over backwards to ensure we were well informed. Our family member was comfortable and they all listened to what was best for him from our point of view. We were shown nothing but respect and kindness throughout the whole time.

Meeting the consultant has made our traumatic experience so much more tolerable. He embodies compassion empathy and the human touch. He has guided my partner and I through his diagnosis and treatment with professionalism understanding and a genuine smile at each follow up. The cardiomyopathy team are amazing but the consultant really stands out for his amazing care.

When patients are admitted into inpatient care, communication with carers and family members can sometimes be patchy. Lack of information is causing carers undue anxiety. This lack of communication can decrease carers' trust in the quality of treatment their loved ones are receiving.

My brother has been admitted a week ago, there is not an update from the hospital, he's constantly in exclusion, no communication at all from the hospital, I have to chase for information. [There is no consideration of his past mental health history and] after a week of admission he's still nervous, not sleeping at all, I am feeling there is not the correct treatment provided.

Our Dad- recovering from a stroke in the Stroke Ward- felt like asking questions about his treatment was an inconvenience to some charge nurses. We witnessed nurses complaining because they were asked to do their jobs by their managers. Other charge nurses would not answer treatment questions or medicine/

observation enquiries made on behalf of our father.

- *Patient's partner has been in hospital for the past 6 weeks and his condition is not improving. She is very unhappy with the poor communication and rehabilitation.*
- *So angry and upset as trying to find my brother who’s been admitted with cancer, and staff have been so cold and unhelpful! Where’s the compassion?*

There were also a few reports of carers not being able to stay near their loved-ones while they were in hospital.

- *Our Dad had a stroke and was ‘treated’ in the Stroke Unit. The staff here are definitely a mixed bag. It is very clear that the Senior Nurses who run the wards have a very difficult time managing non-compliant, non-effective staff members. I witnessed a patient crying for help for15mins whilst a support nurse ignored him. The Senior Nurse had to tell her to communicate with the patient. Despite the Ward Managers authorisation of allowing one family member to remain after hours a staff member aggressively abused her making incorrect statements. Today the ward door was not being answered despite visitors waiting for at least 15 mins trying to gain entry. The day room was also closed for no reason. Patients are not treated with respect by ALL members of staff and family members who are carers of patients are treated as if they are a burden to some staff. This is the only ward that has treated patients and family members with total disregard.*
- *Elderly parent treated in STROKE UNIT. Myself and other relatives visiting this ward have had to call family members inside ward to open doors as buzzer was turned off, after speaking to charge nurse and numerous other nurses nothing had been put into place throughout the day to make relatives or visitors aware that buzzer not working or whether it had been turned off? Just before visiting time ended miraculously the buzzer started working? The room being blocked and buzzer not working leaving many relatives waiting ages before we could gain access to ward was stressful and frustrating. Some elderly relatives /carers were tired going backwards and forwards to waiting area outside ward as only two visitors at a time. Family members staggered the visiting times which allowed relatives 10 minutes each Day so dayroom would not become crowded. My observation was the dayroom has never become full 4/5 people sitting max, what’s frustrating is the nurses are inconsistent with use of room as I have seen them allow people in room but not allow others. Some nurses come*

> *across aggressive and loud, this feels intimidating when asking for an update on patient.*

> *Deceased patient's daughter is unhappy that she was not called by nurses as her mother was declining and her mother died alone as a result. She would like some more information about the circumstances of her mother's death.*

Delays in care (sometimes caused by admin and communication issues or poor planning) result in wasting not just the patient's time, but also that of their carers.

> *A son was informed there would be a delay in his mother's chemotherapy treatment. This delay led to significant distress for the patient and the complainant considers it to be unacceptable. Complainant (the son) found it unacceptable and requested that the arrangements offered by the unit to be changed so that he could phone to ensure the chemotherapy was ready before attending the ward to minimise any potential delays.*

> *My mother, 82 years old, had an appointment at the foot clinic for biometric measurements to be taken. She is Russian and speaks little English. When we arrived, the nurse didn't know the purpose for our appointment and there wasn't a translator present. My husband's impression was that the consultant/nurse was annoyed and didn't feel like doing anything. Surely, we should have been told at our first appointment that a person with fluent Russian language should have been present at the appointment for biometric measurements, I would have taken time off work (although not quite sure why one needs an interpreter just for taking the measurements for the insoles); and the information on the in-house database should have stated clearly what was the purpose of the appointment was.*

> *I am a carer and unfortunately, in that capacity, attend multiple appointments in different depts. The medical staff are great but the system is let down by poor admin, phones that no one answers, follow up letters to GP not being sent for week. Admin staff often lack people skills. Doubtless their job can be difficult and boring but they need to learn to get off their phones, limit their personal conversations and look interested in the patient in front of them. On that basis I might appreciate they are overworked and accept it takes weeks to send a letter but when I see such attitudes when I'm stood there, I imagine, perhaps unfairly, they aren't answering because they are on their mobile.*

In some cases, better communication with carers could have prevented delays (particularly in situations when the patient is not in a condition to effectively express their own needs):

> *My mother has missed two consecutive appointments to the Medical Retinal Service due to poor communication between the Transport department, the drivers and the Retinal Service. There appears to be no communication between the services. There is also a complete lack of understanding when I try to explain that my mother is non ambulant and needs a stretcher for all her appointments to the hospital. Two drivers came to take her to her appointment in her own wheelchair this morning. I have explained countless times that my mother does not weight bare and her adapted wheelchair does not go through her front door. This issue has caused us a lot of time wasting and frustration.*

Furthermore, in some cases, carers are effectively responsible for communicating with health professionals about their loved-ones' needs and following up constantly in order to make sure they receive appropriate care. In some cases, carers feel they need to compensate for the poor communication between different medical professionals and to advocate for their loved-ones.

> *Staff need training in communication- on various wards they don't even write on bed boards by the head; staff need to communicate with relatives and not treat them as children. Doctors don't follow up properly with relatives- what happens to patients who need help to eat when the relative is not there and there's not enough staff? This stresses me out. It seems that there is a lack of communication between staff as well. I even had to tell staff to put a bag on my mother so she could urinate, as she was asked not to move, only to be told if she wets the bed we will clean up. While being taking for her operation I was told I couldn't go any further so walked with staff to lift and said goodbye- very distressing. No one told me when she was out of surgery, I finally get staff to phone only to find out op finished 2 hours ago. Finally get to see her in recovery, then see the waiting room near theatre my heart dropped seeing all the people waiting for their relatives to come out of theatre.*

Scheduling and rescheduling hospital appointments is a task that carers are often responsible for. Poor communication (including poor responsiveness by telephone) makes it more difficult for them.

> *Trying to get hold of the scheduling team on the phone is a complete and total nightmare. I have been trying to call the team for more than a week now to reschedule my dad's appointment to no avail.*

Either the call keeps on ringing or someone picks up the call and cuts off the line very conveniently. I tried calling the central appointment line and they were not able to help me either. If we are not able get through to them then my dad will get discharged and not be given another appointment despite it not being our fault.

Poor responsiveness by telephone also impacts on carers' and family members' ability to stay informed of their loved-ones' state and progress.

I'm very disgusted with ward 14, my mum's been on that ward for 2 weeks, no one ever answers the phone- I ring from 7am to 9pm, how are we meant to check on our elderly mother if no one answers? Don't say they are busy, I've been visiting and seen them sitting at the desk ignoring the phone.

The patient (grandmother) was in ultrasound, her granddaughter was visiting and agreed to be interviewed on her behalf. The patient had been admitted experiencing chest and abdominal pains. The patient received good care and treatment once she arrived at the hospital and the granddaughter said she is the main carer and was well informed about her grandmother's medical condition. She said that family members were trying to ring the ward but they didn't answer, no staff picking up calls, she found this very frustrating and stressful. They brought it up with a staff member she said was touchy about and dismissive.

Case study 1- hospital stay with a child with complex needs

Olanna's son Martin[2] is aged 18 and severely disabled; he suffers from cerebral palsy and requires full-time care. In 2018 Martin has been admitted to the Royal London Hospital for surgery, and Olanna stayed with him at all times. She shared their story with Healthwatch Tower Hamlets Enter and View representatives.

Olanna soon found that the hospital is poorly prepared for accommodating the carers of patients with complex needs, who need to be accompanied at all times.

I'm his main carer and I need to be here. I tried to sleep on the floor on some blankets but it was too cold. I had to ask the manager for something to sleep on. After the third night they gave me a mattress. I'm diabetic and the floor was cold. I had coats on the floor and I was trembling. They ordered me a mattress. The blankets were very thin though so I had to spend my last £20 on getting this nice

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[2] All names changed for confidentiality reasons

thick blanket from the market.

It's really difficult for me to look after him and myself. They won't give me any food as I'm not the patient but I can't afford to buy the food in and around the hospital and friends and family can only bring so much as it goes off and there's nowhere to heat it. I'm not allowed in the kitchen here. It would be great to have a microwave here that I could use. I would clean it. Even a cup of tea would be great or somewhere to make one. Sometimes the nurses sneak me a cup.

It took more than four days to get him a TV. I was constantly checking around the ward to see if one would become free. When I finally got one it took another 2 days to get a card and get it to work. It would be good to have more support for people like me in the hospital. Could the charity do more to support people like me. At least access for tea.

Olanna had to advocate for her son, in order to ensure he gets the care that he needs.

They wanted to discharge him on Thursday and I said you can't discharge him. They wanted to give him different milk than he is used to at home. I said it might cause problems and they should just give him a small amount. I was worried it would make him ill and wanted to wait until I could get his stuff from home. They gave it to him anyway and it's caused him problems. He's been whingeing and he's got diarrhoea.

The nurses are brilliant. I'm not sure the doctors understand the complexities of a patient like my son. They don't necessarily listen to what mother has to say. They think they have more knowledge but I'm the one who's been caring for him 24/7 for the past 18 years. I can give advice and I have expertise it would be good if they would come and sit with me and hear the whole story.

Case study 2- caring for a parent in mental health crisis

Jolene is an older woman living in Hackney and suffering from multiple physical and mental health conditions, who has spent a long time in the Mile End Hospital. She is severely depressed and has had a schizophrenia diagnosis which may or may not have been accurate in the 70's. Negative experiences with some psychiatrists in her youth left her with a lifelong distrust of the medical profession. She also suffers from diabetes and back pain and she is generally frail.

After a ministroke, she became unable to walk unassisted. She is receiving care in her own home through the council, as well as visits from district nurses. When Jolene suffered an accident that caused her leg to become injured, her wound became infected, but she refused treatment. The care she received was unsatisfactory to begin with, but her injury made things even worse. Her daughter and main carer, Martha, saw no other choice but to apply to a court order to have her sectioned, so that she can receive treatment.

Jolene has spent time as an inpatient in the Leadenhall Ward at the Mile End Hospital, as well as the Homerton Hospital. In both hospitals, psychiatry wards did not work well with other hospital departments, which meant a poorer standard of care for her physical ailments. She was initially sectioned and admitted to the psychiatric ward in Homerton Hospital; where staff did not have the proper training to look after her leg injury. They told Martha: *"your mum seems to have capacity/to know what's going on- but she should have been brought into A&E instead, we don't have the capacity to look after her physical health but now that she's been sectioned it's fallen under our responsibility"*. Consequently, on a daily basis she had to be transported on a wheelchair to the hospital's Accidents and Emergencies unit, to have her bandages changed. She had to wait alongside all other A&E patients in the waiting room, sometimes for more than four hours. There was also poor communication between weekdays and weekend staff within Homerton hospital. All these shortcomings effectively increased Martha's workload as a carer and caused her worry and anxiety.

The weekend staff didn't even know my mum was there; she was still in her nightdress, her bandages were smelling because they didn't know or notice they needed change, they forgot to give her lunch.

After Jolene was transferred to Mile End Hospital, the poor standard of care continued. The transfer was poorly managed with pertinent information poorly communicated between medical teams.

My mum kept requesting that her bandages be changed, staff said "only if and when required"- but they hadn't been changed since Monday! She kept requesting paracetamol or other painkillers, but they were not given to her. They refused to give her insulin until the next day!

Part of the complexity of Jolene's case is that Jolene lives in Hackney and Martha lives in Tower Hamlets.

Jolene's discharge back into the community was poorly handled, causing both her and Martha additional stress. The medical team disregarded Martha's concerns, communicated little in regard to the progress of her mother's care and omitted her and her advocate's requested invitation to discharge planning meetings. Jolene has been discharged with an insufficient care package in place, and with insufficient notice for Martha to prepare adequately (including ensuring that Jolene's home is suitable for her to live in, in relation to her impairments and needs. Jolene arrived home to no food in the fridge or meal provision, a prescription to the wrong medication and no suitable bed to sleep in (she had to sleep in an armchair).

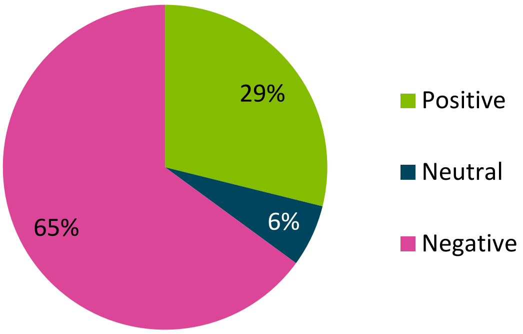
After the hospital discharge, Jolene was not able to make full use of her care package, because of admin and communication issues between stakeholders (local authorities, NHS, the care agency). This increased the pressure on Martha as her carer and next of kin, and made her recovery more difficult.

My mum came out of hospital with a care package in place- but this has been done with no consultation with either myself or her (at the time she had been deemed legally able to make decisions). Care workers were put in place, but it took six months after discharge to get her physio and speech therapy; because they just forgot her in the system. From last year, I kept noticing personality changes in my mum. She stopped letting her carers in and she wasn't managing well- ever since she came back from hospital. I thought we needed to review her care package, but she would say she can do it all herself, and they said she had the mental capacity to make decisions for her own care, so I stepped back. I did try to request a support worker to help once a week with shopping and cleaning, and we never got one. My mum started having a lot of pain, it became difficult for her to walk, she wasn't letting the carers in- carers were constantly calling me to open the door. We tried setting up a tele-care service that would give carers access to keys (through an outdoor key box)- but it turned out no one knew the password and then the keys went missing, so it doesn't work- they still have to call me. We've been chasing this for two years at no avail.

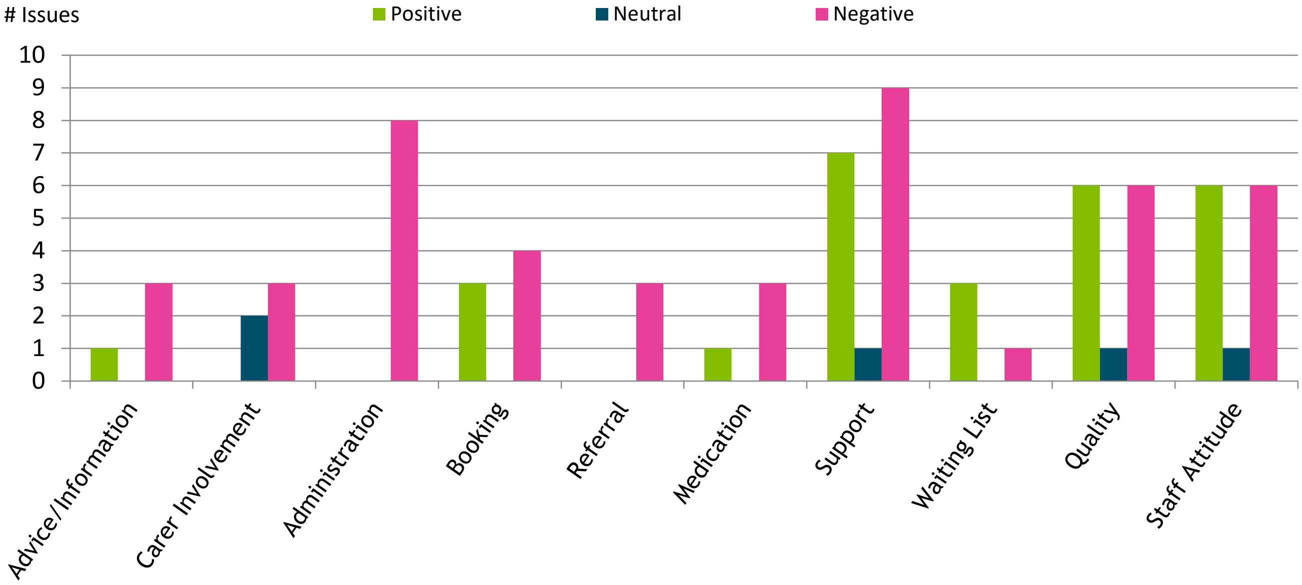
Primary care

From the fourteen carers we spoke to their experience of accessing primary care services (GP and dentists) for their loved-ones were inconsistent, with some feeling better supported than others.

Admin issues make access to care more difficult, contributing to a less satisfactory patient experience.



14 comments, 97 issues
Percentages based on count of issues



It is particularly important for carers and their loved ones to be able to access primary care services promptly and flexibly.

> *Recently I was concerned about my father's health, I had a telephone consultation with a Dr who told me to bring him in for review that same day. The Dr thoroughly examined my father, he was kind, caring and compassionate. He really took my concerns into account.*

> *My GP practice is dealing with a huge increase in patients following the cancelling of their neighbouring Practice's Contract. Their receptionists are under extreme pressure and I would like to mention one receptionist's wonderful kindness, genuine concern and endless willingness to help my 90 year old father with gaining appointments and receiving treatment. I would also like to praise the doctor we see, who works tirelessly to treat large numbers of patients with great skill, fantastic knowledge and extreme politeness. He has been very helpful for my father and I cannot thank him and his staff enough, they are understaffed but do not let this impact on their manner or quality of service, despite vast numbers of patients.*

There are however reports of difficulties accessing GP surgeries.

> *Feedback form young carers' focus groups: receptionists give their opinions "aggression" worked. They think they are a doctor. [Our elderly relatives whom we care for] don't have anyone. They could fall through the system. No one is speaking up for them. Annual health checks have not happened.*

> *The automated booking system no longer works and the receptionists never pick up the phone. I am currently on the phone to the Wapping Group Practice for the past 35 minutes and no one is picking up. I have attempted many times and have to physically go there myself to book an appointment. My mother is extremely poorly and this is not good patient care at all as I am constantly having to run around to book her an appointment by physically going to the Health Centre.*

These can often relate to poor communication between carers and GP surgeries.

> *[Surgeries are] booking appointments without notifying the carer. Since they aren't informing carers, there are missed appointments. They are not involving carers in decisions. They are being slow in noting down who is a carer for someone. Constantly asking "and who are you" and quoting the Data Protection act; Wanting to speak to patient when told not possible.*

Some carers feel that GPs ignore relevant information that they can provide about their loved-ones’ health.

> *My father likes to say he is fine, and his GP takes his word rather than investigating. The GP is dismissive of any information provided by me, his daughter. For example, my father says he finds walking difficult. His GP asked him to take a few steps in his surgery. My father was very proud that he was able to ‘march’ pulling up his knees and standing straight for a few paces! So the GP noted that there were no problems. I was horrified to hear him utter the words, “It’s just old age.” Afterwards my father complained to me that the GP had not offered him any help with transport.*

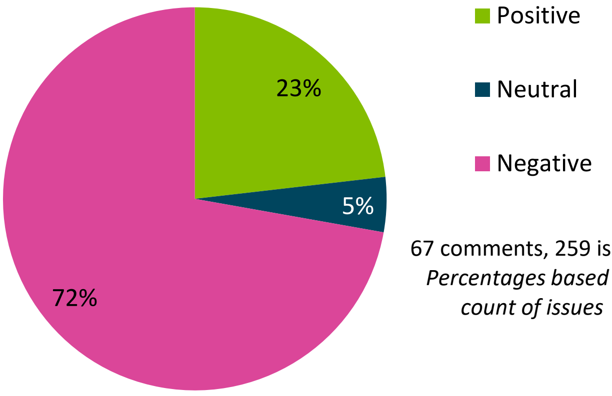
Carers also often take on the responsibility of informing medical professionals of their loved ones’ specific care needs; compensating for poor communication between medical professionals or issues with medical records.

> *The best example is with my mum because my mum suffers from dementia - Vascular dementia – and she's got quite a lot of other medical conditions so we went in to see… relatively new GP. She's a locum or something like that that comes into the surgery… I’m not sure the name. I went and saw her, me and my mum. She prescribed some medications for my mum… She experienced serious side effects so we saw her usual GP, who saw the medication and said, ‘no she shouldn't be prescribed this, I'm sure she's had an allergic reaction to this before’, so then he's gone and looked at her records and said, ‘hang on a second, yes, she's gone and she's had an allergic reaction to this medication before’. Definitely for myself I would generally see whichever GP that's available but for my mum I'm very careful not to take an appointment with another GP.*

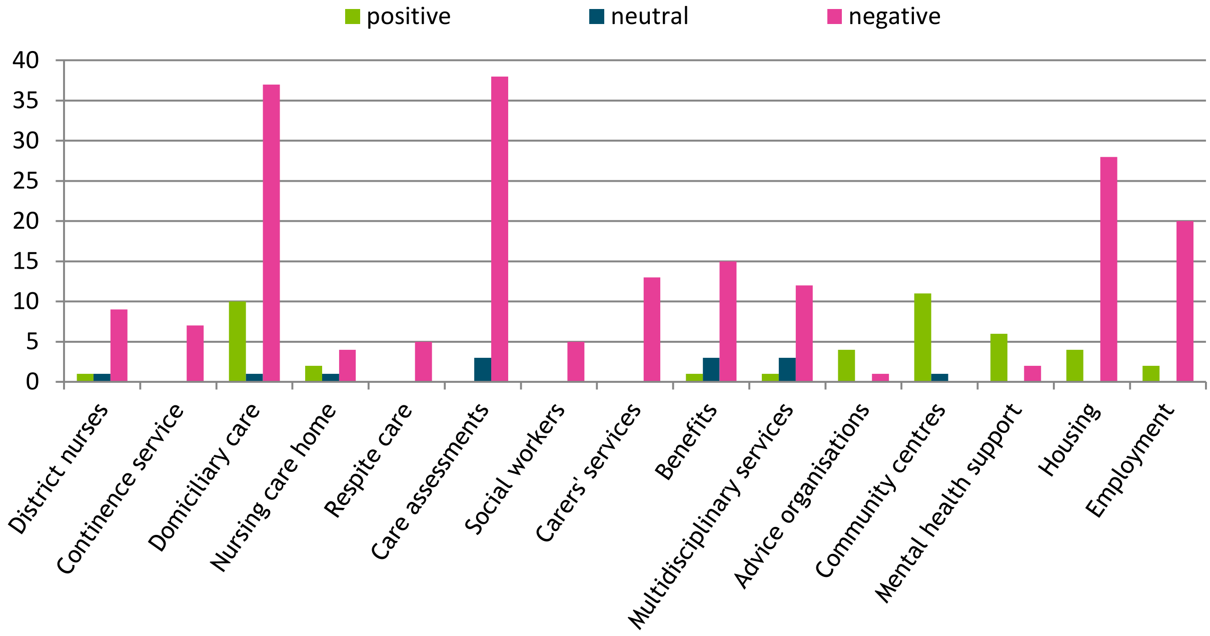
Community and social care

A majority of the carers that we spoke to felt poorly supported both by community health services and by social care services.

Carers perceived that cuts to public budgets, including the NHS and adult social care, meant rising costs for people dependent on care- for example, to access professional care services or day centres. In turn, for those who cannot afford to pay for the level of care they need, this could mean increased dependency on unpaid carers.



67 comments, 259 issues
Percentages based on count of issues



The Carers we spoke to reported that this has a negative impact on carers' health, well-being and finances. Many carers perceive, rightly or wrongly, that access to NHS services or social care is being reduced for their loved ones and to navigate a complicated, non-user friendly bureaucracy affects their mental health. Care-related expenses for their loved-ones add up, impacting on the carer's standard of living and housing. At the same time, caring responsibilities take up a lot of the carers' time, impacting their employability and career development, as employers may not be willing or able to offer them a greater degree of flexibility. Positive comments referred primarily to community centres and advice organisations who alleviate carers' burden by assisting them to navigate a complicated bureaucratic system, as well as to mental health support community groups.

Carers often feel that services don't work well together and don't take their needs as individuals into account.

> *I have an autistic child who is 10 years old and I am having a problem with nappies, we've been using supermarket nappies but they're now too small and causing pain. We've tried using the adult ones, I've tried four different ones but they didn't work. Three months ago, there was a review meeting at Mulberry Place, the CAMHS worker was there and they said they would call the Continence services, but I saw them a month ago and they still haven't gotten back to me. We had review meeting at the school this morning, and the social worker asked me what was happening, and I said that I was going to try and contact the continence service myself. It's frustrating because I can't get through and my son has difficult behaviour.*

> *This lady has a Mental Health diagnosis, CMHT team really need to support their patients who are also informal carers to one or more adults to prevent deterioration of their own wellbeing and refer them for respite support from voluntary organisations. CMHT does not work together with the whole family and often are stopping services without even reviewing their needs and patients are not being told about it.*

Carers also report that provision of community healthcare at home (including district nurses) is poor, making their loved-ones more likely to end up in hospital.

> *[My mother, in her 90's, dementia sufferer, receives care at home 3 times/ day, but] needs more medical care - daily monitoring of her blood pressure etc. I'd feel more confident if we maybe we had the district nurse coming in once a week or every other day. I could cope if I had more medical support at home I think. She doesn't like taking pills and I think she would be better with injections. I try and phone the GP but they are reticent to do home visits. The*

district nurse every other day would be good. Mum's confined to bed at home. Maybe if they could do a drip at home. Just hook her up and keep an eye on her there she wouldn't need to come into hospital so frequently. You get the personal care but not the clinical care at home. It would be good to have both. She was out for six days, discharged and then back in for six days. If it was planned better I don't think she would've needed to come back in.

- *District Nurses – Non -scheduled visits. Very quick and rapid. Rock up when they want. Quite common. District nurses won't come out – constant calling for referrals.*

Carers may be ending or reducing their care as a result of being charged for it, leaving a potential increased burden on unpaid carers.

- *Definitely aware of a number of people who have gone through the financial assessment process and then decided they do not want to continue to receive care and support. In most of these cases, the decision is being taken to rely on 'family support' instead.*

Poor provision of domiciliary care or community healthcare can end up increasing rather than alleviating the unpaid carer's workload.

- *I was caring for my father before he died of cancer. He had throat cancer so he had to have a feeding tube in. I was looking after my dad and the night carers that came to put feeding tube in sometimes didn't turn up to 10 o'clock at night. He'd be phoning me, so I'd have to go around to him, wait there till they came and sort him out and then I could go home. If the feeding tube came out they'd phone me to come to him and take him to hospital.*

- *My grandparents receive care in their own home. My grandma is bed bound. When carers come, not every one of them know how to use the hoist to lift her out of bed. I think there should be an intelligence file for any new carers to review, so that when someone new comes they can do the job. They also leave the sink dirty when they assist her with washing; and sometimes they are late or just don't show up, without letting us know. The least you can do if you're going to be late by an hour or not come in at all is to tell us!*

Communication between carers/ family members with adult social care services can often be poor, particularly around the cost of services.

- *One carer reported that her family had been left with a £2k bill as the financial assessment team had not processed a direct debit mandate. The family believed the money had been being paid. The carer reported that she struggled to speak to the financial assessment team to discuss her case and when* *she did the people she spoke to were really rude.*

I am a carer for my friend who suffered a stroke. He also received some care from professional carers. I am worried that I will have a huge bill to pay. He has had an assessment done to see if he is responsible for paying for the Carers, but I worry that if he is we will have a huge bill to pay. I haven't received any support and face issues when trying to get help for him or ask about his care plan. I am down as his next of kin and I am also his Carer, but they don't tell me the details of his care plan. They say to me that's not the 'procedure'.

My mother had a stroke and there was very little support for her following the stroke and six months afterwards you just get dropped. The process of financial assessment for adult social care charges was not dealt with very well. We got a leaflet with information e.g. if you have investments worth less than £14k and if you have investments over £23K but there was no face to face advice. There was a phone number but you could never get through on the phone. Seven times I tried to get through on the phone. I tried to email. We just got a final assessment. We got through on the phone in the end and they just said "Hello - yeah, ya gotta pay it" It was a bit cold. The first month you were given an invoice and no way of paying it. It said they will take by Direct Debit after the first month but there were no details for how to pay the first month. It feels like they haven't thought the model through. Dad gets upset and stressed. I didn't see anything in the letter about independent advice.

Poor communications from the Financial Assessment Team [around changes in the policy]. Felt like the policy was rolled out without any communication. Carers questioned the level of consultation with carers around the implementation and rollout of the policy. Carers criticised the tone of the letters that were initially sent out in October. The Carers criticised the professionalism of the Financial Assessment Team when speaking to them over the phone. General feeling was that they are rude and have a bad attitude. Carers were unaware of the generic Financial Assessment Team mailbox email address. This needs to be made clearer. Lots of different communications being sent out to people – e.g. letter and financial assessment, invoices, service user statement, benefit letters (people don't often distinguish between council and government departments like DWP). Felt it was very confusing to keep track. (Similar feedback received from local voices)

Caring for their loved ones' impacts upon the mental health of carers and family members. Lack of support from NHS and social care services can worsen it further.

> *My husband's cancer diagnosis- It affects the children. But I have had support from people. They are helping me a lot. Because if you have too much, it can destroy your brain, it makes you like mental illness. But good luck. I don't put a lot in my brain! People think I'm laughing, I'm happy, but in there I got a lot - I am carrying a lot!*

In some cases, carers are dealing with their own health issues. Caring responsibilities make their situation more difficult.

> *My friend has suffered a stroke, I'm his carer and he is currently in hospital. I have also been in hospital. He is being discharged today, even though he does not have suitable accommodation, but the hospital still want to discharge him because they need the bed. He can't get about and needs round the clock care. How they determined he is well enough to go home I don't know. He is partially blind; he is just waiting for the opticians to officially certify this. He does have a care plan in place and carers do go in, but 45mins is not 45 mins more like 20mins. They have to stop and write reports and this eats into the time which he should be receiving care. I worry that as I am still in hospital that he will be very lonely and can't stop his mind from wondering off. Loneliness can lead to depression. It's a big issue. But the hospital know all this and still want to discharge him, because they need the bed. I was looking after him for 3 months and I am exhausted.*

> *[Son of patient with care needs] said he felt tired and 'burdened' as he had to be called away from his workplace unexpectedly when she initially fell ill and that he is not getting enough support for his own health care needs.*

It can be difficult for carers to juggle their employment and their caring responsibilities. As chronically ill people become unable to work and starting to need care, while, at the same time, their spouses, children or other relative may find themselves unable to work full-time as well, as they need to care for the ill or disabled person; this can easily result in families having their income significantly reduced and sliding into deprivation.

> *My husband was working, but then he was diagnosed with cancer, and we started having financial difficulties. His feet were swollen, it was so hard for him to go to work, he can't work. I tried to look for a job, I couldn't get because it is so stressful, it's hard for me to get. Because if you are going to ask someone for a job and they know your situation, have to*

> *tell them frankly because if you have to go for an appointment they won't allow you, isn't it? Tell them frankly, they have to know your situation. So it was hard for me to get a job.*

> *I used to look after my dad and he got cancer of the throat and he couldn't eat so he had to have a feeding tube put in. I was self-employed at the time doing my therapies… I was doing different jobs before that. I was working pubs, I was working in restaurants and cafes. Most of the restaurants, it was cafes. I was doing whatever I could to earn a bit of money. [My biggest challenge in the past two years…] I think not having the work because that's your outlet from everything else. You can't take your things to work because it was therapies, you're helping other people. You can't go in, 'oh god, this is happening.' You can't talk to anybody about it, because it's not done. They can tell you, you can't tell them.*

> *[From carers' focus group: what doesn't work well] Job Search Interviews. Unnecessary if you are a carer. Finding jobs suitable and tailored for carers. Jobs with flexible hours. [They should] Recognise caring as a form of employment. Offer learning for young carers (18+). Offer Qualification for carers. (These should not always be in regard to caring). Create a protocol for carers to search for work. Offer a range of work beyond caring. (Offer employment options that can help a carer secure a role in jobs other than caring)*

> *I was teaching. Teach adults short courses and I was working on a zero hours' contract. My money kept going up and down. I gave up my teaching to be… I was also caring for my brother. My mum- he lives with my mum. He was beaten up- he's an adult- so he was left mentally disabled so she's looking after him but then in the later years, he got liver cancer. So on top of everything else, he had difficulties, he had to be taught what to do where to go, how to wash, everything. He couldn't be left; he'd wander… I was doing that around my work but then his appointments got more and my hours went down, so in the end I gave up my teaching and became the full-time carer which is 62 pound… a week.*

Accessing benefits can be a challenge for carers.

> *When my dad had cancer, before he died, I was working as an adult trainer. I wanted to claim tax credits or carers for him, but because you're self-employed it works differently. You have to give them your accounts. I was doing it myself and you can imagine the papers… I wasn't earning loads. It was just enough to get by… it was just me.*

Poverty and underemployment result in a lower standard of living and poor access to suitable housing. Chronically ill people (who may have specific housing needs) and their carers struggle to afford to rent privately, so they depend on social housing and housing benefits. Obtaining these can be a long and complicated process.

> *[From a carers’ focus group: things that don’t work well]. Not suitable accommodation, just temporary solutions. Lack of help for private renters. Paying major bills £10k plus when someone’s elderly and you’re a carer. Issues re Housing Benefit and bedroom tax for temporary or wrongly provided accommodation – no central system. (Council put the patient into 3 bedroom instead of 1 bedroom and had to pay). Carers being housed outside of the borough, in Hackney. Unsuitable temporary accommodation for people who suffered life changing impairments and now require accessible accommodation. Not undertaking assessment of people who have suffered life changing injuries/illness and their housing situations before discharged from hospital (Stroke team and social services team discharged patient to unsuitable accommodation, then they made patient homeless). Solutions are not practical for carers such as rehousing only cared for and not the carer. Carers are being moved around without practical consideration. Could carers be given priority consideration when applying for housing for loved ones? (For housing to not give housing according to just the service user, they must also consider the carers needs.)*

Community centres and advice organisations provide a crucial service in supporting carers to manage with practical aspects, such as care assessments or money matters.

> *I called the Bromley by Bow centre and they made me an appointment. I went over there and I spoke to J******** She was really nice and really friendly. She did what she could. She couldn't really do a lot for me, but when I spoke about my mother she said okay this stuff we can help there. So thereby helping my mum, she was kind of helping me. […] So I phoned them up, got the appointment, talked through everything, wrote down my income and expenditure, so it was clear for them. She said, ‘I can see that you've done as much as you can… I’ll see what I can do.’ And it was putting in help for the extra rent, the DHP - Discretionary Housing Payment. She got in touch with the landlord- the housing association HARCA. She spoke to them and said look, she's applied for the DHP, but because there is nothing on the system… because I was telling them and they weren't listening to me. They listened to her, because she's official. She knows what she's talking about, they'd listen. I was just a tenant. [She supported me to chase up my DHP application]… Mum’s cooker was going and*

> *they got her a grant for £300, paid into my mum’s bank, so she could get that. That helped her and took the pressure off of me. she recommended the grant from here and they filled in all the forms and mum had to sign this form, we sent it back, and that was good. Plus, they helped her with the water bill, they halved it. Because apparently some criteria where she’s over a certain age and she's got illnesses and all that… and you get half price the water bill. I didn't know about any of that before, she was good.*

> *Sure Start gave me a voucher for food bank. Because I didn’t know what to do, they give me food bank, actually. And then I get someone to support me there in food bank. He said he can help me to sort out my situation, to help me with everything. He helped me to call the advisor people, call ESA people. They told me to get a paper from the doctors [about my husband’s cancer and my own chronic illness]. I told them each and everything, yeah. I got benefits after three months.*

Community organisations can also combine mental health support for carers with practical help, empowering them to develop coping strategies and gain practical skills.

> *[I became interested in mindfulness and counselling after experiencing difficulties in life, including having to care for my elderly mother and getting into debt]. Learn to deal with it yourself and then you can show others properly. That's what I did. So I went and did a course. The Idea Store said yes, you can teach this. So they paid half towards the cost and I did that and you had to stay with them for a couple of years to teach this course on top of the other ones. The paper work got quite a lot. Fill in this, fill in that. And then they used to phone me out to other places as well… when they had an open day I'd be the one doing head massage… then they’d get a nice sum for it, and I’d still get regular hour’s wage.*

Case study 3- care at home for a vulnerable adult

Abdul[3] is a Bengali resident of Tower Hamlets in his 80's. He suffers from Alzheimer's, chronic back pain and from various age-related physical impairments, which mean he needs daily personal care. He is illiterate and only speaks Sylheti. His daughter, Rehanna, and son in law, Tariq, do not live locally. In January 2018, Tariq spoke to Healthwatch about his situation.

Tariq said that care workers from the XX agency, who were looking after him, took advantage of the fact that Abdul could not read to falsify records and did not perform the full extent of their duties.

> *The care worker used to come every day- that's what they were supposed to do. But last year, we only had one care worker attached for my father in law. The carer only came three days a week and said on the log book that he was coming every day. They also didn't provide personal care like my father in law needed. We complained to the agency and the care coordinator, and got a different care worker from the same agency. When he was asked to do personal care, they said it wasn't their job.*
>
> *He's a vulnerable adult and care workers can fool him; you know… He's illiterate, he doesn't speak English, he can't check what they are writing on the timesheets and doesn't know where to go for help when care workers are not supportive.*

There was a sense from Tariq that this situation did not only arise because of individual workers not doing their jobs; but also, under-resourcing and poor communication between social workers, the care agency and individual workers. All of these factors contributed to Abdul not receiving the care he needed.

Social workers from the Council assessed Abdul and determined that he needed help with personal care, such as dressing and washing. However, Tariq did not feel that the care workers were trained or supported to perform these duties or that the social care team verified that the care needed was actually given.

> *The social worker didn't explain [to the carer] what personal care is- the worker just made tea and gave him his medication. Tower Hamlets social workers are not enforcing what [care workers] should be doing; I think they have good relations with the care managers and don't want to spoil them- that's why they*

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[3] All names changed for confidentiality reasons

> *don't want to be firm about respecting the care plan. Care agencies make a fortune from their relationship with the Council, and the Council can't be bothered to do any monitoring or enforcing.*

Lack of support from carers has consequences for Abdul and his family.

He is becoming more socially isolated, as he is not supported to attend age- and ability-appropriate activities that could otherwise keep him active and involved in his local community.

> *My father in law has been entirely house-bound for the last few weeks; he can only rarely see friends and family in his own home. His care worker provides no personal care, no shopping- nothing like that. I think he feels lonely and isolated…*
>
> *He used to go to a gardening project in Mile End Hospital- a minicab took him and dropped him off. Now he can't, he's been too ill. If a carer took him in a wheelchair, with some assistance he could still do it- but a service like this is just not available. He does go to the day centre- they provide transport and wheelchairs. I think he would like to have a buddy, someone who can talk to him; he doesn't get many visitors.*

The burden of care also falls on Abdul's family. Rehanna, his daughter, had no choice but to take on the responsibility of practically managing Abdul's carers, verifying them and ensuring they are providing the care that they are supposed to provide, as well as constantly dealing with the care agency and with the social workers from the council.

Instead of freeing up time and energy for unpaid family carers, this type of situations ends up creating more work for them.

> *My wife needs to keep in constant contact with the care worker and the agency- she needs to be her father's unofficial social worker and hold the care worker to account- it's like a second part time job for her.*

Greater awareness of flexibility for patients and their carers in using their care packages could be a solution to this problem; as it would allow them greater control and it would create the framework for a more personalised service.

> *We would like to have a personal budget- would be better to appoint our own workers for his needs- but the social worker told us that would take a longer time than using the agency.*

Initial Response from Local Authority Adult Social Care

The council's approach is that nobody should be forced to care and they have increased investment into preventative support for carers. The Carers Centre have been funded to provide:

- dedicated benefit support and welfare advice for carers.
- a service at the Royal London Hospital to support with the identification, awareness and support to carers (including out of borough).
- Support small employers to support their staff with caring responsibilities,

Medical professionals and social workers carrying out care assessments should specifically seek out and take into account relevant information from patients' family members on the patient's specific care needs; particularly if the patient is not in a condition to communicate on their own (e.g.: young children, learning disabilities, dementia, language barrier, acute distress.

Adult Social Care has introduced the role of Carer Champions and ELFT are proposing to recruit to 3 carer champion roles

Local authorities and the DWP should improve communication with patients and carers around the cost of social care, particularly newly introduced charges and eligibility criteria.

The Council has, and will continue to, work to improve communication around social care charging and eligibility criteria.

Local authorities should allocate further funding for community centres, carers' centres and advice organisations to support carers with advice and casework around access to social care, money matters, applying for social housing and benefits, employment rights and employability.

Council has increased investment into carer services

Employers should offer carers more flexible arrangements so that they can remain in the workforce for as long as possible

Resource purchased for SME and GP practices to support staff with caring responsibilities. Including a joint lunch and learn during Carers week that was open to health staff