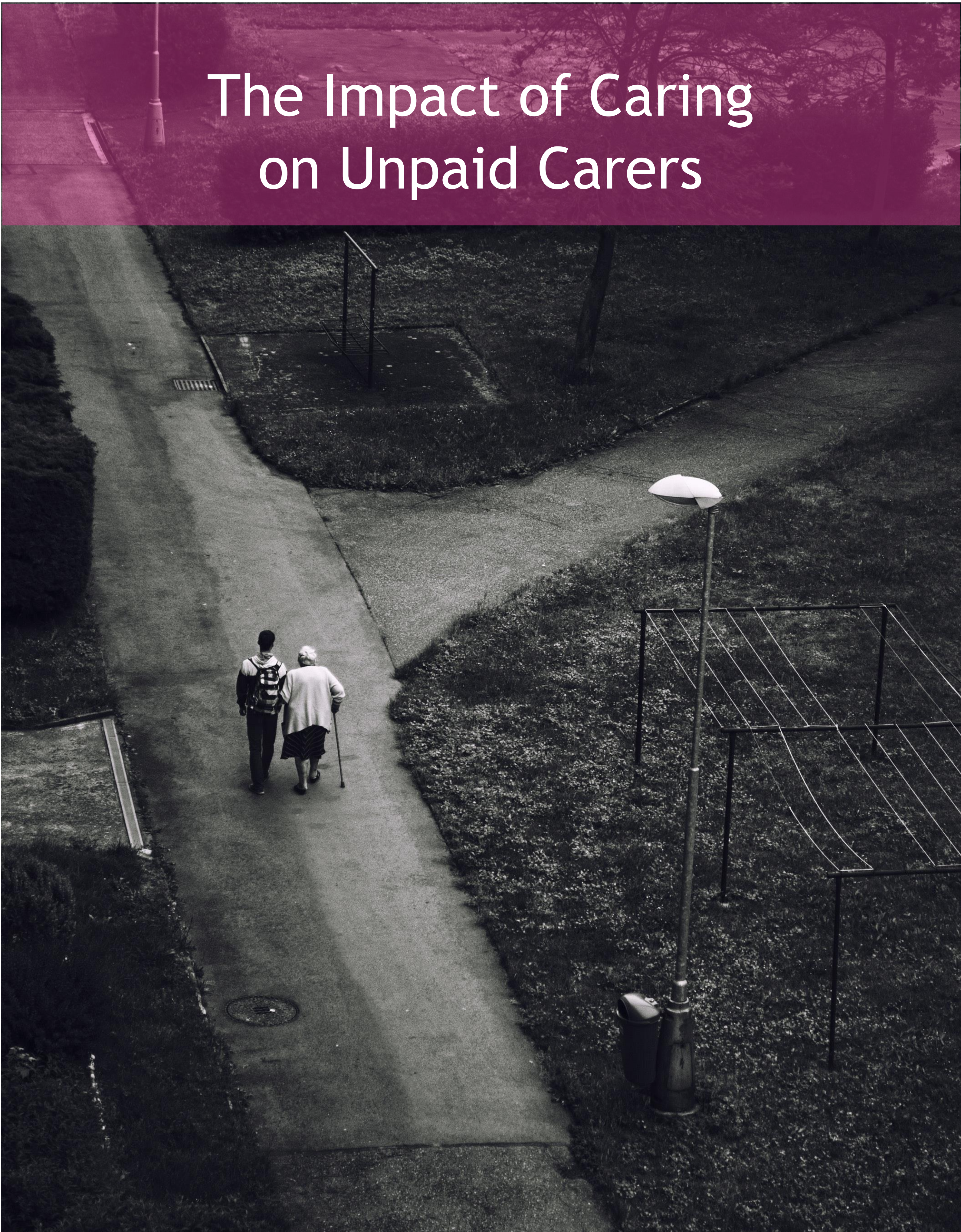
healthwatch
Southwark

2020

The Impact of Caring on Unpaid Carers



Contents

What is Healthwatch Southwark?

There is a Healthwatch in every area of England, and an umbrella body - Healthwatch England. Healthwatch is a statutory function funded by, but independent from, local authorities. Healthwatch Southwark is part of Community Southwark, a charity which works with the local voluntary and community sector (VCS).

Our vision is for Southwark residents to be able to access and receive the best possible health and social care services, appropriate for our diverse communities.

We are the independent champion for the patient voice. We…

- provide information and signposting
- promote patient and user involvement
- listen to local people about your needs and experiences
- voice patients' and users' views and concerns in order to make services better.

Why we looked at the experience of carers

'The impact of caring on unpaid carers' was chosen in early 2017 as one of five priority areas for Healthwatch Southwark's engagement work: https://www.healthwatchsouthwark.org/report/2017-04-30/our-new-priorities-201718

We had heard that support available to carers in Southwark was very limited, difficult to access and not widely known about. The impact on carers' own physical and mental health was felt to be significant. We understood that the pressures on carers' resources meant they might have few opportunities to be heard. Yet unpaid carers are a crucial lynchpin of the health and social care system.

Supporting initiatives to help carers

As well as finding out about the experiences of carers, we hoped to be able to increase awareness of support available to carers in the borough, and to connect important initiatives.

We therefore got to know organisations supporting carers directly, including Southwark Carers, where we participated in a number of Carers' Cafés. We also visited the Alzheimer's Society.

We visited St Christopher's Hospice to discuss Coach4Care, an initiative that trains ex-carers to coach others currently looking after someone with a life limiting illness. Coaches help carers develop positive coping strategies to improve their resilience, and to provide them with opportunities to reflect on their situation and improve their own wellbeing and that of those they care for.

We also visited Bell House to discuss Learning to Care, a project that educates people on various aspects of caring for and supporting their elderly family members, friends and neighbours, through a series of talks and short films.

We will make use of this information in our signposting function and are planning an event in early 2020 both to launch this report and to share information about support.

How we listened to people's views

Healthwatch Southwark developed a survey to investigate the experiences of unpaid carers, the support they receive and further support they would like, and the impact that their unpaid carer role has on their life and wellbeing. During survey development, the Healthwatch Southwark manager sat on a panel at Southwark Carers, along with medical professionals, a local Councillor, and a representative of Neil Coyle MP, to hear about challenges faced by unpaid carers in Southwark.

We defined an unpaid carer as anyone who looks after somebody who needs regular help with their daily life because of their illness, frailty, disability, a mental health problem or an addiction, and cannot manage without a carer's support. This does not include parenting care without these additional challenges. The carer might be an adult or a child.

The survey was open to anyone with unpaid carer responsibilities, where either or both the carer and cared for person lived in Southwark.

The survey was launched in late December 2018 and ran until April 2019.

In order to publicise the survey and identify possible focus group candidates, we:

- posted a paper copy to 313 Healthwatch Southwark members aged over 45 or without an email address
- distributed a flyer at community venues and via Southwark Carers
- used our websites and social media, especially Twitter
- connected with about 25 voluntary organisations via email and personal contact
- at the Alzheimer's Society, connected with individuals who helped to publicise our work through the Southwark Dementia Action Alliance
- attended events including Southwark Carers' Christmas Party, Southwark Carers' Mental Health Forum and Carers' Café, a Hub for Older People, Disabled and Carers engagement workshop, and King's College Hospital patient engagement meetings
- presented/circulated information via both King's College Hospital and South London and Maudsley Trusts, Southwark Council, the Community Councils, and the two Southwark GP federations
- requested our Advisory Group's support to publicise the survey via their networks, including at Southwark Disablement Association.

Overall, 63 unpaid carers responded to the survey. 8 responses were excluded as they gave no responses beyond the initial demography. 55 responses were analysed.

Four focus groups were also conducted: one with a mixed group of 4 carers (at Southwark Carers), two group of two carers (at Southwark Carers and Cambridge House), and one group of 11 young carers - 4 boys and 7 girls aged 8-12 – during their monthly Saturday drop-in session with Imago Community at the Surrey Quays Shopping Centre.

Additionally, four unpaid carers who could not join a focus group were interviewed, using the same questions and format as were used for the focus groups.

The findings from our focus groups and interviews are presented in this report separately from the survey findings, inside text boxes.

Summary of findings

Healthwatch Southwark aims to represent the views and experiences of the public as accurately and directly as possible, sharing them with decisionmakers in order to enable the best possible services to be developed.

Using a survey method with a qualitative focus allowed us to capture the diversity of carers' thoughts, feelings and experiences across a range of topics, including their private lives, interactions with other people, and within the local context. Detail about people's experiences of health and care, and the personal meanings of these experiences, can provide valuable insights for service managers, clinical commissioners and health policy makers to design and develop more appropriate services. We have made recommendations to assist commissioners and service managers in Southwark with developing services that can promote a positive experience of caring, and mitigate the negative impacts.

There were 55 respondents to the survey, and 12 participants in the focus groups and interviews, all of whom were over 18 years old. There were 11 participants in the young carers focus group, all aged 8-12. Therefore, we have explored the experiences of adult and young carers separately.

Adult carers

The carers that responded to the survey were primarily caring for one person only (69%), living in Southwark (93%) with their cared for person (64%), and aged between 36 and 64 (69%). They were mostly caring for their parent (42%), child or adult child (28%) or spouse/partner (14%). Most (64%) of the cared for people had a physical disability or health condition. Many cared for people also had conditions related to frailty and old age (36%), mental health (32%), dementia (26%) and a learning disability or autistic spectrum disorder (24%). The majority (58%) of the cared for people had multiple conditions across more than one category (see Appendix 1).

1. **The impact of caring on unpaid carers was extensive, emotional and intense.** Most carers were providing many different types of support for long hours, beyond personal care. Some also had to be watchful and alert during the night. The majority of carers reported a negative impact in most areas of their life, including their physical and mental health, relationships, employment and personal fulfilment. The impacts felt hardest by carers were those that deteriorated. These included sleep deprivation and tiredness, chronic stress and anxiety about the cared for person and their future, and loss of personal time to self care or build relationships. Caring also had a two-pronged financial impact, in that there were extra costs associated with caring, such as food and laundry, but many carers were unable to work more than part-time or go for promotions. Those caring for someone with dementia or a complex mental health condition faced specific challenges, such as aggressive behavior from the cared for person, being excluded from care, or their children witnessing traumatic events.
2. **Communication with health and social care services compounded the emotional experience of care.** One-off interactions with individual professionals (such as GPs, social workers and district nurses) could have a positive effect on how supported carers felt, and the trust they had in a service. Conversely, difficult communication was not just an additional challenge, but compounded the carers' feelings of isolation, stress and hopelessness. Across the study, many people described the Council's communication and support as inconsistent, unresponsive to their needs, and lacking in empathy. This meant they did not trust the Council and some carers were even afraid of contacting Social Care services. Many carers took on care coordination responsibilities and found their journey through the health and social care

system disjointed and filled with waits and silences, requiring them to continually push for appropriate support.

3. **Carer Assessments did not seem to be working for carers**. A large proportion of the carers surveyed had not had an Assessment, sometimes despite requesting one, and the overall process did not seem transparent. Those that had gone through or completed the Assessment process said that the assessors could be disbelieving and uncaring, and that they sometimes received no communication about the outcomes. Others said they had to seek out support themselves rather than being signposted, or that the support offered following an assessment was not appropriate. There was a sense of abandonment among many.
4. **Carers valued a personalised, varied model of support but very few people were accessing this.** From the VCS, this included one-off or occasional support such as advocacy or help applying for benefits, as well as ongoing social events, peer support or counselling. Some carers were receiving support from their friends, family, neighbours or colleagues with respite care, household tasks, and emotional support. These informal support networks were highly valued by those that had them. Some carers felt their faith made them more resilient, but caring responsibilities made it hard to keep attending church. Where it was accessed, VCS support could enable people to continue caring, and was even described as lifesaving. Some wanted training specific to their cared for person's condition, for example communicating with someone with dementia. Flexible access to respite was also important. Carers needed time for 'life administration' tasks, as well as longer breaks to de-stress. However, poor experience of respite care was a barrier to enjoying breaks. Many who had taken a holiday had a family member or friend look after their cared for person, which tended to mean they felt more confident and relaxed.
5. **Counselling helped carers to understand and cope with their role.** Access to counselling was crucial for carers to 'unbundle' and manage complex responses to taking on such a demanding role for someone close to them. However, cost, waiting times, and difficulty getting out of the house were all barriers.

Young carers

All the 11 participants in our young carers' focus group were aged between 8 and 12 and caring for a sibling with a learning disability or autism, or a parent with a mental health condition.

The main themes were:

1. **Caring was difficult but seen as one, among other, childhood problems.** Caring itself meant some young carers struggled to socialise and had less time to themselves, or time for schoolwork. Having someone in their family with an illness or disability also made some the target of bullying and meant their home life was less stable, for example if they moved frequently. Overall, the young carers were more positive about caring than the adult participants and tended to view it as part of life, as difficult as their friend moving away or pet dying. Sometimes caring made carers different to their peers in a positive way, as they had more responsibility and knowledge. However, this may not reflect the experience of adolescent carers or those not engaged with a support service like Imago.
2. **Support at school, hobbies and activity groups, and respite were highly valued.** Most of the young carers spoke about a trusted teacher they could talk to, and some had short meetings within the school day with support services. The young carers talked extensively about the activity clubs they attended as spaces for personal time, fun and socialising. Most of the young carers had respite planned, which they saw as a break from their daily lives.

Context and next steps

In summer 2019, Healthwatch Southwark was invited to join a Southwark Council Carers' Project Board, which is guiding development of a new Carers' Pathway and support for carers at upcoming Hubs for disabled people and for older people. We were also pleased to be able to contribute to the Carers' Joint Strategic Needs Assessment (JSNA) Task and Finish Group. JSNA is a process by which local authorities assess the current and future health, care and wellbeing needs of the local community to inform decision making.

At the Carers' Board, we discuss with Council officers how services should develop based on what we have heard from carers, and we make suggestions about where further engagement should take place. We submitted early drafts of this report to the team working on the JSNA so that the themes could be incorporated, and commented on the early drafts of the JSNA. We now hope to support the development of recommendations to be included in the JSNA, which will be published in early 2020.

Our own recommendations, as set out below, reflect the experiences described by carers, as well as some of their own suggestions for improvements to services (see page 37.) We know that some are in line with the former Carers' Strategy, *Valuing Carers in Southwark*, and projects now underway. We look forward to hearing commissioners' and services' responses regarding what measures are already taking place and which recommendations they intend to act upon. The recommendations in this report are therefore part of an ongoing dialogue with the Council and other services, which we hope will lead to the best possible outcomes for carers from new pathways and services.

As part of this dialogue, Healthwatch Southwark will be holding an event for carers in February 2020. As well as sharing information about support available, we will present the findings of this report, and hope to be able to include updates from commissioners and services about their plans. Carers will have a further opportunity to comment and discuss what matters to them.

Healthwatch Southwark will request to present this report (and the event report) at the Southwark Health and Wellbeing Board, on which we have a seat. We will also share it with our local MPs.

Recommendations

It is necessary for services and commissioners to acknowledge resource shortages and existing gaps in support for unpaid carers, whilst fully recognising their contribution and wide-ranging needs, whether or not these can be met directly by statutory services.

There needs to be ongoing development of an imaginative and wide-ranging continuum of support at different levels, building on community and personal assets available to carers.

In order to achieve this, there needs to be attention to identification of carers, clear communication about services, rights and processes, and holistic needs assessment and signposting. There also needs to be investment in services in line with the huge value of carers – but there are a wide range of low-cost support systems which can be fostered.

1. Develop the culture and leadership around supporting carers

Southwark Council

a. As part of your ongoing review of services for carers, refresh your commitment to fully supporting carers with openness, understanding and collaboration, with strong leadership from management. This should recognise explicitly that investment in support for carers is a key preventative approach with probable high returns.
b. Share both this report and the JSNA with frontline staff and managers.
c. Develop further materials and events in partnership with carers to build trust and awareness of challenges.

2. Improve communication with carers

Southwark Council

a. Ensure information you provide online and in leaflet form contains clear detail on:
    - Support: the variety of options available (statutory and community), with examples, so carers can understand the purpose of signposting and assessment and ask for what they need.
    - Assessment: different types of assessment/signposting discussions and their role in establishing eligibility (see 3a below), how to request assessment, how to get advocacy or support through the process of assessment, what an assessment will involve, the right to request a separate assessment to the cared for person, and timings for outcomes.
    - Respite: legal rights and eligibility, how to request respite support, different types of respite care, and issues to consider when planning respite (including that provided by family and friends).
    - Expectations for frequency of contact with professionals, particularly social workers.
b. Review information materials in partnership with carers to ensure the overall tone is appropriate and reflects your mission (1a).
c. Widely disseminate information at community venues, GP surgeries and hospitals.
d. Provide specific displays for carers' information at the Hubs.
e. Collaborate across the Hubs in developing an online directory of appropriate carers' support (not limited to carer-specific organisations) with clear service offers and referral pathways, to be used by the public and frontline staff. Work with service users and carers to ensure it is accessible and useful, and consider developing specific staff posts to maintain it.
f. After establishment of the new Hubs, pay continuous attention to how well they and the existing Wellbeing Hub are meeting the identification, signposting and assessment needs of carers.
g. Ensure that GPs, other frontline staff, and carers' champions (see 2h below) are able to refer carers for assessments and to Hubs for support.

NHS Services (GP Federations, GPs and hospitals)

h. Develop carers' champions to identify, support and signpost carers seen in frontline services. As the model for social prescribing is developed, led by the GP Federations, strongly consider inclusion of carers as a priority cohort for support from coordinators based in GP surgeries.
i. Disseminate information about support via the GPs' carers registers.

3. Refresh the Carer Assessment process

Southwark Council

a. Work in close partnership with carers to develop holistic discussion guides/forms for professionals to use when signposting and assessing carers. Notwithstanding legal requirements about the content of statutory Carer Assessments, the two types of discussion should be as integrated as possible and viewed and presented on a continuum, rather than as a black and white test of eligibility for all types of support.
b. Ensure that holistic signposting discussions:
    - Cover all relevant aspects of carer activity and wellbeing including the areas mandated in law for the statutory Carer Assessment. We suggest specific attention to sleep.
    - Take into account different types of need for respite (e.g. regular short breaks, longer breaks to relax, supported breaks with the cared for person).
    - Take an asset-based approach *without* assuming that all carers have existing assets, or giving the impression that this is aimed at reducing the support offered.
    - Also examine current and future *risks* to carers' assets due to their caring role (for example difficulty socialising, attending faith groups, or staying in employment).
c. Review with frontline Adult Social Care (ASC) staff whether there is enough time to conduct adequate assessments for carers as well as their cared for people, and make changes if necessary.
d. Develop staff skills to conduct holistic assessments by learning from other initiatives (e.g. Care Coordination pathway, Integrated Care service, Age UK Safe and Independent Living (SAIL), and social prescribing).
e. Ensure systems are in place for appropriate reassessments to take place – to identify deterioration (e.g. age-related increasing needs), following changes in circumstances (e.g. hospital discharge) and at other points of transition.

4. Meet more carers' support needs

Southwark Council (particularly via the new Hubs) and NHS providers (GP Federations, GPs and hospitals)

a. Trial methods for actively supporting carers to develop their own informal support networks. For example, 'buddying' systems, hosting and signing up carers to peer groups (which could combine online support with in-person meets), and basic support for individuals to build group activities themselves.

Southwark Council

b. Commission and develop a voluntary initiative or brokerage platform (similar to South London Cares or GoodGym) where volunteers build a relationship with carers and their cared for people, and can provide befriending, practical support (e.g. with household tasks), and potentially short-term sitting (for brief respite).
c. Investigate funding for and provision of digital support tools, such as the Carers UK Digital Resource for Carers, or mental health and mindfulness apps.

d. General signposting of carers should naturally include potential referrals to talking therapies and counselling support.
e. Signpost carers to specialist training, for example manual handling/lifting, promoting better sleep, de-escalating challenging behaviour, effective communication, and understanding conditions and signs of deterioration.
f. As Work Well will no longer be funded, explore and publicise options to support carers to find and maintain appropriate employment. This could include guidance to local employers on carer-friendly practice.
g. Ensure that when providing respite care, time is allowed for good handover between unpaid and paid carers, and guidance on what should be covered (suggestions are included in Carers UK's materials).
h. Following completion of the JSNA, review the state of funding and outcomes for carers' organisations and carer-specific support. This should take into account the large numbers of (mainly unidentified) carers in the borough as well as their huge financial and social contribution.

Southwark CCG and Improving Access to Psychological Therapies (IAPT)

i. Consider providing specific peer group therapy options for carers, and the option of home visits for those that cannot leave their cared for person.

5. Continue improving care coordination

Healthwatch Southwark will continue to engage with ongoing work across the health and care system to improve care coordination. We have two specific recommendations around appointments:

a. **Hospital trusts:** Give good notice and flexible timing of appointments.
b. **GPs:** Consider offering double appointments to enable carers to see the doctor at the same time as their cared for person.

6. Further investigate the experiences of carers in Southwark

Southwark Council

a. Compare the experiences of carers from diverse backgrounds, in order to highlight inequalities that should be addressed as a priority. This requires further identification of carers by Southwark Council.
b. Engage with young carers to understand their experience, including those not currently receiving VCS support, and teenagers.
c. Look in depth at the reasons for poor health among carers (e.g. sleep issues, difficulty attending appointments, financial problems).
d. Engage with carers to better understand experiences of respite care provided by paid-for and statutory services.
e. Investigate the experiences of carers during their, or their cared for person's, transition from child to adult services.

Our findings in detail

The responsibilities of our survey respondents

Number of individuals cared for

Of the 55 unpaid carer respondents, 69% (38) cared for one person, 24% (13) for two people, and 8% (4) for more. In total, our 55 carers provided support to 78 people. We asked for detail only about the first two cared for people (i.e. 72 people).

Carers' sole or shared responsibilities

We asked whether survey respondents shared care for their cared for person(s) with another unpaid person. 40 carers (72%) were the sole or main carer for one person and 9 (16%) for more than one person. In a minority of cases (14% of the 72 cared for people), another carer helped equally or more.

Types of support provided by unpaid carers

Carers were assisting in many ways with people's daily life and health, with 87% helping with the most common area, household tasks, and nearly half providing help with even the least common, nursing care.

Types of support provided by carers	Number of carers	% of 55 carers
Household (e.g. shopping, laundry, cleaning, cooking, paying bills)	48	87%
Care coordination (e.g. making appointments, following up with services, communicating with professionals)	46	84%
Mobility assistance (e.g. to medical appointments, social activities)	45	82%
Emotional	42	76%
Personal care (e.g. washing, dressing, toileting, feeding)	34	62%
Nursing (e.g. catheters, giving medicines, monitoring blood sugar)	26	47%
No response	2[1]	4%
Total number of carers	**55**	**100%**

[1] These people both specified later that they provided 24/7 care.

Specific examples of nursing care given included managing epileptic episodes, and 'supervising care and maintenance of specialist equipment, e.g. bipap machine, wheelchairs.' Examples of household support included 'Replacing objects that go wrong, reporting anything that goes wrong in her home and being there for repairs etc.' We also asked about any other types of care provided that we had not listed. Several respondents mentioned administrative and legal support (including Legal Power of Attorney), supporting the cared for person to socialise, and cognitive stimulation.

To get a sense of the range and extent of support provided, we also looked at how many types of care were provided by each individual carer. The large majority were active in many areas of their cared for person's life.

Number of areas of support provided by carer	Number of carers	% of 55 carers
0 types of care specified	2[1]	4%

1 type of care specified	3	5%
2 types of care specified	2	4%
3 types of care specified	6	11%
4 types of care specified	12	22%
5 types of care specified	12[2]	22%
6 types of care specified	18	33%
Total	**55**	**100%**

[1] These people both specified later that they provided 24/7 care.

[2] One of these people then specified that they provided 'all' types of care, but had not ticked 'emotional support'.

Carers who provided support in every area stressed the responsibility of this situation - 'All care responsibilities are on me', 'I do every single decision to keep him safe and happy.'

Hours of care

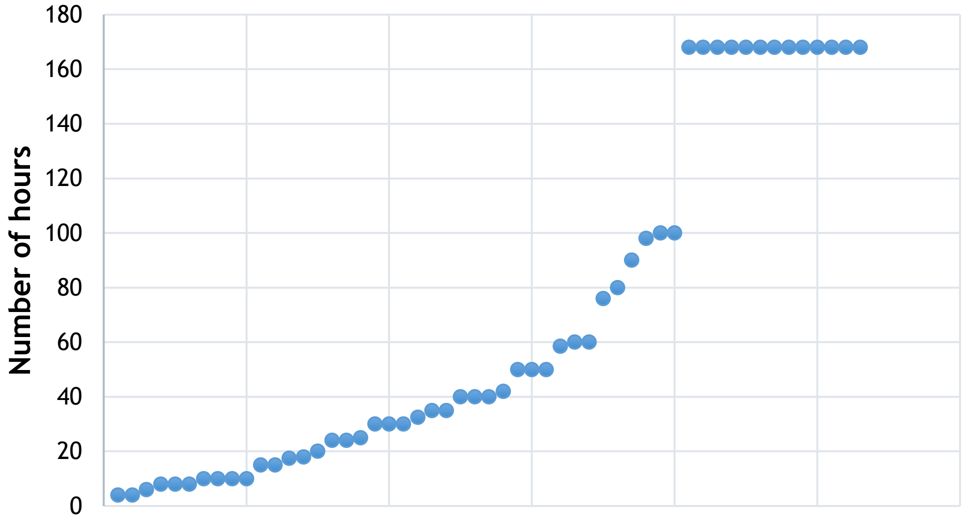
All of our carer respondents were giving up substantial time to support the people they cared for every week, ranging from 4 to 168 hours per week. For the 53 people who specified the hours of care they provided, the average was a heavy burden of 69 hours per week. One person explained why 24/7 care was a reality for them, 'Overall care throughout the day to include being watchful during sleeping hours.'

Hours of care per week	**Number of carers**	**% of 55 carers**
Less than a working day of 7 hours	3	5%
8 to 35 hours	21	38%
More than a working week of 35 hours, but not 24/7[1]	16	29%
168 hours (24/7 care)	13	24%
No response	2[2]	4%
Total	55	100%

[1] The maximum given was 100, which is essentially most waking hours.

[2] These were not the same people who did not tick any areas of care, and they later referred to a high burden of care.

Hours of care provided by individuals in an average week[1]



[1] Each blue dot represents one of 53 people who responded to this question. Where people gave a minimum or range of hours, the minimum or midpoint was used.

Communication with professionals

We asked carers to rate how well the professionals involved with their cared for individuals communicated with them and kept them updated. We asked people to think about 'all sorts of services from carers, to GPs, district nurses, social workers, physiotherapists, clinics, or staff caring for the person during a hospital stay.'

Professionals communicated…	Number	% of 55
…very well	2	4%
…quite well	10	18%
…mixed/neither well nor poorly	19	35%
…not that well	6	11%
…not well at all	14	25%
No response	4	7%
Total	**55**	**100%**

The results present a mixed picture, with 22% of carers reporting a positive experience of communication, 35% a mixed view and 36% negative experiences. In many cases, people's consideration of 'communication' led them to discuss care and support more widely.

Adult Social Care (ASC) and other Council services

Several carers described **significant communication challenges** with ASC teams. One carer referred to 'social workers' inconsistent communication', and another explained, 'Well I have [not] heard from my son's social worker since 2017. He once came for an assessment or review, but I did not hear of the result.' Another commented on communication style, 'Adult Services are cryptic and patronising.'

'Caring on its own is okay, but if one has to deal with the irresponsible way things have been done by Southwark Council, then life becomes unbearable. I am so disheartened.'

A carer who was looking to gain more **control over their cared for person's services** expressed concern, stating 'I have been trying to get Direct Payments for months… but this has turned to deaf ears.' (It is unclear whether there were issues around consent.)

Several carers also left general comments about the **non-responsiveness of the Council to their needs.** A parent carer looking after an adult child with autism, obsessive compulsive disorder (OCD) and learning difficulties stated, 'I am very unhappy with the way I have been treated. Have had no support from Southwark Council.'

Another carer who was receiving domiciliary care help responded, 'They also insist not to increase care hours despite his complicated medical health'. Another noted, 'I am… most disappointed with Social Services as I am yet to receive assessments following hospital discharges… In the main it is the nurses, physios and occupational therapists on the ward who support and advise us.'

Some carers experienced lack of response from the Council while going through critical challenges, 'I have also requested Sheltered Housing and a move to a two-bed ground floor flat… I too am ageing and need to support [my cared for person] on the stairs - bearing her weight, all of which is falling to deaf ears.'

More positively, one carer described **Southwark Information, Advice and Support Team (SIAS),** the Council's 'arms-length' impartial information and advice service, as an 'ally' in meetings with their daughter's school about her Educational Health and Care Plan and special educational needs support.

'The [care home] room was extremely dirty...I reported this to the Social Worker and waited for weeks without response. I then emailed again without any response.'

Focus group and interviews: views on Adult Social Care (ASC)

The carers tended to be more positive about **individual social workers**, than ASC as a whole, 'My husband has a good social worker who I keep in touch with - I feel relieved.'

Several carers felt that 'they' (the Council and ASC) **did not listen** and were **not there to support them**:

> 'Social Services ignored my calls for help initially.'
>
> 'They were not there...I felt more than let down.'
>
> 'Whatever you are reporting, they don't hear it. I asked the council if there was any training, but there was none offered.'

Others felt **ASC waited for the worst case scenario**, rather than offering preventive support:

> 'We are self-funders, so [ASC] wasn't involved...I thought I should get on their radar, so I got in touch. It was a 10-minute call: 'Ring us back when you run out of money'.'

There was a sense of **distrust**, and sometimes a belief that ASC was **working against them:**

> 'Social Services relocated my son without consulting his family… I was accused of being an unfit mother.'
>
> 'Whatever you say, [ASC] always use it against you. I've always got a witness and I always write things down.'

A couple of people seemed **afraid of contacting** ASC, in case they reduced their support:

> 'I am always worried that if Social Services visit to conduct a review my son's care package would be reduced...even when you know that your situation has deteriorated and need more help, you do not mention it.'

Young carers: views on Social Services

Several participants shared their experiences with Social Services and the Council, which were all to do with **housing**. One had picked up on her parent's negative experience, 'social workers have not been helpful, my mum had an argument with the council – housing problems.'

A couple seemed to have taken on board their **parents' wariness of the Council,** 'Social workers want me to move to another room from my sister who I care for. I don't want to move but my mum and dad said I should to avoid problems.'

However, another young carer said the Council was 'kind of helpful' as they had seen a wheelchair and shower seat provided for their sibling.

GP surgeries

Feedback on how well general practice teams communicated with carers was **generally positive,** with comments such as, ‘GP good’ and ‘GP…communicate[s] well with me’. A carer of an elderly parent with cancer reported that ‘exceptionally good communicators include our GP practice, not least the practice nurses’.

‘GPs are very supportive when I access them, but you have to have the energy to be proactive and if you look capable of managing, they leave you to get on without help.’

Possibly reflecting **a limited role played by GPs in proactive care coordination** for some people, a carer explained, ‘the GP is very good, but I only see him if there is a problem; [otherwise] occasional assessment from surgery nurse’. A parent carer of a young person meanwhile commented that ‘the GP is very rarely involved and lacks specialist knowledge.’

Focus group and interview feedback: GP surgeries

Similarly, there were **mixed views about GP support** with some GPs described as 'very good’ or ‘supportive’, but others as unaware of carer’s needs:

> ‘I had a breakdown to the GP that was not handled well.’
>
> ‘The GP had nothing helpful, information or resource wise.’

District nursing

We received **conflicting descriptions of communication by district nursing teams**: a carer of an elderly partner with cancer and a kidney condition commented that, ‘district nurses communicate well with me’, whilst the carer of an elderly parent with dementia stated, ‘district nurse service communication is appalling’.

Hospital staff

A carer of an elderly parent with cancer, stroke and macular degeneration highlighted the ‘exceptionally good communications with our palliative care and myeloma consultants and cancer nurses, and more generally the staff at Guy's Cancer Centre, and the St Thomas' A&E consultant.’ Another carer left positive feedback stating, ‘Communication is normally good at King’s College Hospital A&E’.

A couple of carers were troubled by ‘slow’ or poor communication around their loved one’s hospital care, explaining, ‘Some poor [communication], for example the disregard for content of the ‘This is me’ template and SALT feeding plan during an admission.’

Care coordination and transfer of care

Some carers described **negative communication experiences with health and care services in general**, for example referencing the ‘poor communication and wait times.’ A full-time carer of a friend with dementia identified broad **issues in connecting with support services**, possibly reflecting a consent issue, ‘I have struggled to hear from Social Services, Age UK and clinics.’

‘We have not been communicated with very well and the system is confusing and often unsympathetic about the carer needs and stress levels.’

A few carers described the need for their **own proactive involvement in care coordination**, with one exclaiming, ‘I have to push everyone for information; it is never easy - nothing is ever straightforward.’ A parent carer described the difficulties in coordinating her daughter’s care, ‘I have to initiate communication and liaison between community healthcare services and school.’

Hospital outpatient **appointment coordination** was rated positively by a carer who said, ‘The medical side of care is extremely good, giving sufficient notice and times and dates of appointments well in advance.’ Another, however, said that it was ‘difficult to coordinate appointments when I work full time.’

Others also noted **communication issues between different services**, for example mentioning ‘slow communication between social services and carers, and also hospital and home’. Another referenced the shortcomings of **data and IT arrangements**, stating ‘The biggest communication problem is the extent to which the 'data systems' don't talk to one another, e.g. GP surgery to local hospital.’

Transfer of care (discharge) was a window when communication was especially important. Carers who had **positive experiences** said timeliness/planning and the involvement of all relevant professionals was important. One described an ‘early at-risk hospital discharge arrangement between consultant, GP and me’ as ‘exemplary’, and another valued ‘good communication from occupational therapist and physio.’ The benefits of good communication are seen in this carer’s experience, ‘Following hospital discharge this time, the nurses got us linked to the Rapid Response team who, for the first time, managed to get someone out on the same afternoon and next morning to support me in the change of care.’

Medicine management following discharge could be stressful. One carer explained, ‘Following hospital discharge this time, there was a mix up with the medication which had changed, and I was expected to understand and manage this on my own. Pharmacist was closed, hospital had not given me the correct drugs and there was nothing that could be done, subsequently, she returned to hospital the following day.’

The pressures which difficulty in coordinating care placed on carers also stood out among comments from our focus group participants when we asked our final question about their impression of support as a whole (page 36).

‘They are very quick to criticise and jump to conclusions.’

Transition between children’s and adults’ services

A few carers identified **transition from children’s to adults’ services** as a time when communication was especially important. A carer supporting a daughter who was about to turn 18 stated, ‘It is unclear what services are available locally for a young person in transition.’ The parent of a person with autism said, ‘As soon as someone becomes an adult, it changes overnight and although you want them to take responsibility, at the bad times you are left trying to organise anything from benefits to medication and stepping in when they are unable to cope and there is no one to help, signpost or guide you the carer through the maze of authorities.’

Two carers also highlighted the difficulty in **no longer having full access to their cared for individuals’ full records**, following their transition to adulthood. One carer commented, ‘As my son is now fully grown, I get no information at all.’ Another observed, ‘Since my daughter is [now] an adult, she does not allow professionals to communicate with me.’

Domiciliary care and care homes

We also heard **conflicting views on communication from paid carers.** A carer of two parents both dependent on domiciliary care said, 'London Care are absolutely atrocious and breach health and safety etc.', whereas another commented, 'The NHS side is weak in communication. [Paid] carers are better.'

Focus groups and interviews: views on domiciliary care and care homes

A few people described **needing to keep an eye on the care** provided by professional services:

> 'My father experienced bad care from underpaid carers in short time slots...I would highly recommend a little webcam.'
>
> 'I make sure the carers turn up at night times – I keep following up.'

Carer Assessments

Carer Assessments are used primarily to find out whether carers are eligible for support from the Council, but can also lead to signposting to community sources of support. We asked respondents whether they had received a Carer Assessment from or through the Council. The majority (75%) had not.

Have you received a Carer Assessment?	Number of carers	% of 55 carers
Yes, by Southwark Council	8	15%
No	41	75%
Don't know	5	9%
No response	1	2%
Total	**55**	**100%**

Experiences of not having a Carer Assessment

Several people said they had not had an Assessment because it was 'never offered' or they were 'never asked'. In some cases, this seemed to reflect a sense that their role as a carer, and the challenges of caring, were not being recognised.

'My cared for person's team have never acknowledged or assessed me as either a young carer or now as an adult carer.'

Descriptions suggested that getting an assessment is **not a transparent process**: some people felt that they had to be invited to an assessment to have one, whereas others spoke about requesting it themselves, or being referred. Another respondent explained that they **did not see the point in applying** for an assessment because 'I don't believe it'll be successful as my daughter's application for PIP was unsuccessful.'

A few people mentioned **requesting an assessment but not receiving one**, despite having asked for this multiple times. The lack of response or follow up could be frustrating. One person said, 'They never come to assess me… they did not do any carer assessment of me from 2015'. Another carer described how they had been 'sent for a carer's assessment to Southwark Carers by my doctor, and by the Wellbeing Hub' but felt rejected, 'I have been turned away every single time as they are not interested in helping me at all.'

Lack of follow up and transparency seemed to extend into the assessment process, with people who said that they had *not* been assessed referring to having started the process, or their assessment perhaps being out of date.

'They never tell you or send you any report for assessments carried out.'

Carers often spoke about the Council or ASC as a **'they',** for example 'they never come' or 'they never tell you'. This suggests the Council might be perceived as an opponent to carers, rather than an ally.

Only one person who had not been assessed described seeking alternative support to fill the gap, 'I have since sourced my own support via Great Ormond Street Hospital and SLaM [South London and Maudsley] Talking Therapies.'

Focus groups and interviews: Carer Assessments

Nine participants (75%) said they had received a Carer Assessment from Southwark Council, again with some never having been offered this.

They felt the **assessors were uncaring** and the **lack of communication** left them in limbo:

> ‘[They] were unprofessional, uncaring and blasé – nothing phased them. They said there were no resources, nothing much we can do.’
>
> ‘The focus was on saving money.’
>
> ‘[They] never send families assessment reports, care plans or call to inform you if funding is approved...you could be waiting and suffering.’

As in the survey, **provision** did not seem to match what was needed, ‘I was offered three things: a one-off grant of £250, counselling, 40 hours of free respite for one year. The reality was, a cheque was sent and there were rules about what it could and couldn’t be spent on.’

Experiences of having a Carer Assessment

While one respondent said the assessment was ‘very good if late in the day’**, most of the comments were negative**.

A few people said the assessment itself **did not fully grasp the extent** of the carer’s role, ‘The assessment doesn’t really take into account what the carer is doing.’ Another person described said that ‘the person doing the assessment was pushy/unbelieving’ – if this is the case, the **onus is on the carer** to prove they deserve support, which was described as ‘very stressful’.

Another respondent said that they ‘hate carer assessments’ because they ‘have been assessed more than enough’ but ‘nothing ever comes of it’. Like those who had not been assessed, the respondents experienced a **lack of follow up or tangible outcomes** from ASC, ‘I don’t even remember if anything happened afterwards...I don’t have a yearly assessment.’

‘It was 3+ years ago and I’ve not yet understood the outcome, despite asking for more information.’

Other assessed carers felt the **support they had been offered was not appropriate** for their needs. One person felt that they needed more respite or paid carer support but said the ‘Council sells hard with ‘better in a care home’ argument’. Revealingly, another added that assessment ‘was a token exercise… I wanted a support group but all I got was a £200 cheque.’

‘[Assessment] was a ‘token exercise… I wanted a support group but all I got was a £200 cheque.’

Carer’s Allowances and costs of being a carer

Carer’s Allowance is a national benefit payable to some carers (depending on their circumstances and how much care they provide), and currently stands at £66.15 per week. Of the 55 respondents, 35 (64%) told us they were not receiving a Carer’s Allowance, and 19 (35%) were (one person did not respond).

Focus groups and interviews: Carer’s Allowance

Five focus group/interview participants (42%) were receiving a Carer’s Allowance, and the experience could involve **unpredictable changes** in the money:

> ‘My Carer’s Allowance was stopped when my [cared for] husband and I went abroad for health respite, but it seems not to have been restored.’
>
> ‘They started paying me £60 per week, then wanted it all back because they had under assessed my dad.’

Extra costs associated with caring

We then asked, whether or not someone was receiving a Carer’s Allowance, whether there were any costs associated with being a carer that they paid for themselves (i.e. that were not covered by any allowance).

42% of carers stated that they faced extra costs, including both people who did and did not receive an Allowance.

	Extra costs	No extra costs	No money to cover unmet needs[1]	Don't know/ no response about extra costs	Total
Receiving a Carer's Allowance	8	2	1	8	**19**
Not receiving a Carer's Allowance	15	6	0	14	**35**
No response about Carer's Allowance	0	0	0	1	**1**
Totals	**23**	**8**	**1**	**23**	**55**
Totals as % of 55	**42%**	**15%**	**2%**	**42%**	**100%**

[1] One respondent receiving the Allowance recorded no extra costs but explained, ‘I don't have the money to play with at all, to pay for anything that isn't covered by the allowance given to me. Even though I need it.’

We asked people to estimate the extra monthly costs associated with caring, and 12 did so. Costs ranged from £30 to £400, with a high outlier of £1500 (to fund a care home and travel to visit). The most frequent values were £50 and £200.

Two people mentioned **paying for care directly** - a care home, or emergency care cover when the carer was ill. However **extra transport costs** were most common, affecting over half of carers with extra costs, to visit the cared for person or to take them to medical and other appointments. This included a mix of public transport, petrol and taxis.

Around a quarter of carers with extra costs mentioned **food.** As well as having to purchase general food for the person in their care, a couple of people specified that they needed to buy ‘diabetic food’ or ‘convenience food’, ordered online.

Several people mentioned extra **utilities and bills**, such as ‘large electricity bills’ due to their cared for person’s needs. Another mentioned large phone bills. **Laundry and cleaning** posed a burden for several people, with one family having had to buy a new washing machine and dryer, and another carer saying the ongoing costs added up.

‘[I pay for] weekly laundry, as the washing of bedding, clothes etc., drying, ironing, is beyond me. I am currently spending between £17-20 weekly. I have not calculated the cost of cleaning materials to include soap powder as this is a constant.’

A few carers had paid for **aids and adaptations**, including ‘new furniture and grab handles’ or ‘incidental aids and adaptations… [for] pain and symptom relief, food and eating, mobility, sleep, home safety — anything from a magnifying reading light to organic cotton sheets to a walk-in bath.’ Several others said they had to pay for **medications and treatments** and **incontinence pads.**

Several carers saw **loss of employment income** as an extra cost associated with caring, with a freelance worker saying they had lost earnings, and two saying that caring limited their working hours – ‘I had to change to part time, 3 days a week instead of 5.’ Another person referred to ‘indirect costs as I’m not able to take up a better paid job.’

One person explained that the Allowance provided to them was not adequate to the purpose of **keeping them well, including taking breaks**, ‘Carer's Allowance is the only payment I receive for me and on its own would be insufficient to meet my own personal needs as a carer. These include keeping fit, mentally and physically; eating well and taking short breaks.’

Non-statutory support systems

Hoping to find out more about people's support systems beyond social services, we asked respondents whether they received any support from 'any groups (e.g. at a hospital) or voluntary/charity/community organisations.'

Three quarters of the carers surveyed were not receiving any support of this type, and only twelve people (22%) were.

Sources of support

When we asked for further information, eleven different support organisations or groups were mentioned, with some people getting support from more than one place. Nine of these were **voluntary and community organisations**, and two were **NHS trusts**. The most frequently mentioned was Southwark Carers.

Organisation	Number of mentions
Southwark Carers	7
Citizens Advice Southwark (CAS)	2
Alzheimer's Society	2
Carers UK	1
Homestart	1
South London and Maudsley (SLaM) Talking Therapies	1
Great Ormond Street Hospital (GOSH)	1
CARERS4CARERS	1
Lambeth Carers Hub	1
Myaware Kids[1]	1
Advising London	1

[1] Support for children with myasthenia and their parents

Impact of support

We asked how support groups and organisations had helped carers. Respondents described **two broad types of support: one-off and ongoing**.

CAS and Advising London were identified as sources of **one-off advocacy and advice**, specifically around claiming benefits and 'applying for government support'. Alzheimer's Society and Carers UK were said to help 'a bit' with **information and referrals**, and Southwark Carers was a source of information for two respondents, one of whom said that the newsletter was their only source of external support.

In terms of **ongoing support**, people described organisations giving them the chance to **socialise**, providing **respite care** or 'time for me', or offering **counselling**.

Two people said that Southwark Carers helped them to be less isolated, for example by organising 'social gatherings with other people'.

> '[Southwark Carers] gives me support and focus to continue caring. I get to attend a choir.'

Notably, a couple of carers described a **patchwork of organisations**, with each providing a bit of support in different ways. For example, one got information from Southwark Carers, advice from CAS, support specific around their child's illness from Myaware Kids, and could 'also speak with the Family Therapist at GOSH'. They said, 'I know where to go for support if I need it', which suggests a model of support that might boost **resilience and self-efficacy**.

Focus groups and interviews: support from the voluntary and community sector (VCS)

All but one (92%) of the participants had some experience of support from the VCS, including peer support, leaflets, and assessment support, but this is likely to have been biased by how the participants were recruited - many were approached at voluntary organisations like Southwark Carers. Other organisations mentioned included the Alzheimer's Society, Chaucer Resource Centre, CAS, Dementia UK and a housing association.

Several carers felt that that good VCS support had been **lifesaving:**

> 'If I didn't have this [volunteer role at Southwark Carers], I would have committed suicide by now.'
>
> [Alzheimer's Society] were my saviour really, being there as a network for support...calling regularly to check if I was OK.'

A few carers had found it valuable to understand their loved one's condition, through **training** courses on communication with people with dementia and information about mental illness, 'I have now changed my attitude towards [my son] and I am determined to help him.'

However, often carers had to invest their own **time and energy** to find and maintain support, which could be a barrier:

> 'I was too overwhelmed by my caring responsibilities to go seeking that much needed support.'
>
> 'There is no one place to go to for carers' support'
>
> 'It was about me Googling and looking for numbers. That's how I found out about Southwark Carers – the Council never told me about them.'

Young carers' focus group: support

Aside from Imago (where the focus group was held), almost all the support the young carers described was located at **school**. Imago is able to arrange short sessions with young carers during school hours, 'one-to-one to check in'. Place2Be also provided 15 minute 'space to talk' sessions at schools, 'if there was a problem you could talk to [them]'. **Trusted teachers** were also important figures:

> 'Whenever I tell my teacher something, she always understands and tries to cheer me up. I trust her.'

After-school clubs and hobbies were described in detail by the young carers, with several taking turns to list all the things they did and when during the week. Clubs and hobbies seemed to provide structure, regularity and fun, 'I go to The Salmon Youth Centre [in Bermondsey], we do football, table tennis, rock climbing...'

Focus groups and interviews: counselling

Eight (67%) of the participants had received some counselling or therapy, including through SLaM, the VCS, their college, or privately.

They felt counselling helped them to deal with **complex, carer-specific** issues:

> '[Talking Therapies] really helped me unbundle about being a carer'

> 'I felt bad about the resentment that I had for my mum.'

However, there were **barriers** to accessing counselling, such as waiting times or difficulty leaving the house:

> 'I eventually had one year of private counselling at £50 per session, and I put the one-off [carer's] grant [of £250] towards this. Although I had paid for sessions, I was unable to leave the house on several occasions to attend some of these.'

Informal support networks

Several people said they had more informal support, including from friends or peers, 'compassionate neighbours', 'spiritual support' or online support. In general, informal support differed from formal in that it seemed **more small scale and continuous.**

For example, one carer explained that their neighbours helped by taking their 'husband out for walks' and 'generally communicating with us both'. Some suggested they purposefully avoided more formal support, 'I have chosen, so far, not to attend groups.' One respondent felt that Alzheimer's Society provision was 'disgraceful' and had therefore helped to set up their own support group, 'We now have our own group that meets once per month...to get some ideas, brainstorming on what's out there to help.'

Focus groups and interviews: informal support

Nine (75%) of the carers described having some **informal support**, mainly from family, as well as friends, colleagues, and people 'who had been through a similar journey':

> 'I found support from my co-workers...[they] helped to look after my husband whilst I was running errands.'

Respite

Respite is any break that a carer has from their responsibilities – this might mean an hour or two here and there, or a longer holiday. It usually involves support being provided to enable the carer to take time off. They might go on holiday alongside their cared for person (with support provided to help them relax), go out or away themselves, or have the cared for person go somewhere else (such as a day centre or on a holiday themselves).

We asked carers about the most recent respite holiday they had taken from their caring responsibilities.

47% had taken respite since taking on their caring responsibilities, but 38% had not.

The average duration of this break was 7.5 days, but breaks ranged from one day to four weeks. A few people described having regular planned breaks, for example going away 'every 6 weeks for a weekend', or their cared for person being taken on holiday once or twice each year.

	Number of carers	% of 55 carers
Took respite, in…	26	47%
…2019	5	9%
…2018	10	18%
…2017	4	7%
…2016	2	4%
…2015	0	0%
…2014	1	2%
…2013	2	4%
…date unspecified	2	4%
Never taken respite	21	38%
No response	8	15%
Total	**55**	**100%**

Carers who had not had a respite holiday

Some people who had never had respite, or had not had it for a long time, said this was because they **did not know** 'such a thing was available', that their cared for person had become 'too ill' or because they had 'no support'. One person hoped, since their mother had recently moved to a care home, that they would be able to go on organised respite through Southwark Carers – perhaps rather ironic.

A **younger carer** who had never taken respite felt that it was more important as they got older to build and maintain social connections, 'As I am 18 years old now, I'd like time away with friends.'

Sources of respite care

We also asked those who had taken a respite break who looked after their cared for person while they were away.

Who looked after cared for person?	**Number**	**% of 26**
Relative	14	54%
Friend	3	12%
Extra support from a home care service / private carer	3	12%
No one, they coped with their usual services	3	12%
Care home	2	8%
Other	3	12%
Total carers who took respite	**26**	**100%**

Over half (54%) of the participants who had taken respite had a **relative or relatives** that looked after their cared for person while they were away. Two of these people also organised additional support from a home care service or private carer.

Of those who marked '**other**', one specified a 'cleaner and some family', another, a personal assistant (funded by direct payments), and one, carers from social services 'who come three times a day' (it was unclear whether this constituted extra support in addition to the usual service).

Experiences of respite care

We asked carers about their experience of respite care, and whether they had had any concerns. A couple of respondents suggested it was **difficult to prepare** in advance of their break, saying it was 'hard work to leave'. One carer, whose daughter (the most vulnerable cared for person) was looked after by her brother (the carer's son, who also had support needs), was particularly concerned about them eating properly, '[I] did a lot in preparation for my break, so that my son wouldn't need to go shopping'.

A few respondents mentioned that they **struggled to switch off** during respite because they were concerned about their cared for person. One carer said they were 'worried', and it was therefore 'hard to take a real break'; '[Respite was] nice but was still worried about my mother.'

However, several carers attributed being relaxed to their cared for person being **looked after by someone they knew well and trusted**, such as a close friend or relative, 'My other daughter looked after her sister, so all was fine.'; 'No concerns as it was my best friend providing the care.' One carer said they had no issues and concerns about their parents' care as they had been able to arrange their sister 'taking over from me.'

Relatives and friends can help provide **continuity of care, but in some cases this can still be an issue,** 'The physical environment away from the cared for person's own home can be challenging [and] less well adapted.'

An important concern raised by a few carers was that **their cared for person's health deteriorated** or was set back while they were away. One person described a very negative experience with respite at a care home, 'It was a disaster and I had to work a lot to bring her back to her previous level of health and mobility.'

In one case, respite being provided by a friend did not result in adequate support – the carer's son 'ended up in hospital one day after I returned' as an illness 'wasn't picked up'. As a result, the carer **no longer felt able to take respite.**

'No more time away again for fear he will get worse again.'

One carer felt the **break was not long enough** to really make a difference to their mental wellbeing, 'I don't feel the duration was long enough. I still felt stressed when I came back.' A few respondents also mentioned **using daylong breaks away from caring to do important tasks** (e.g. job interviews, hospital appointments, or to 'catch up with family or other commitments') rather than for personal relaxation. It is likely that some carers **require two different types of respite**: shorter regular breaks for general 'life administration', and longer breaks that allow the carer to truly de-stress.

Focus groups and interviews: respite

Four carers (33%) had taken respite in the previous six months. Again, this ranged from ‘odd days away only’, to more substantial breaks.

Regular respite was seen as essential, but it was mostly **self-arranged** (and sometimes self-funded):

> ‘I paid for a carer to come on weekends to give me a bit of respite.’
>
> ‘The only respite I got was what I arranged with my sister... this was invaluable for me and without it, I probably would have ended up in the Maudsley.’

Several people said there were **barriers** to accessing respite through the Council:

> ‘The locum social worker who reviewed [my cared for person] ...only reviewed the hours of support, which she cut and did not mention any of his other activities, so we lost them. My respite was also withdrawn.’
>
> ‘When I asked [ASC] about respite, I was told ‘We don’t do that no more’.’
>
> ‘At no time whatsoever did any of the many professionals involved talk to me about respite or my needs.’

Young carers’ focus group: respite

Most of the young carers were having a **respite** break this year, except one who said, ‘I’ve never been on holiday’. Two were going to stay with other relatives, two were going on school trips, and two were going to activity camps - one of which, Over the Wall, was specifically for young people with serious illness and their siblings. These breaks were described with excitement, and as a departure from daily life, ‘It’s for physical and mental health, and getting away from it all.’

The impact of being a carer

We asked carers to rate the impact that their caring role had had on various aspects of their lives.

Whilst the 55 detailed responses presented a mixed picture, they did show a strong trend towards ‘negative’ and ‘strongly negative’ impact on all listed aspects of carers’ lives.

Over half of the participants registered a negative impact on their mental health, financial situation and employment situation, as well as household management and time to themselves.

Nearly half reported negative impacts in the areas of physical health, relationships with others, and personal fulfilment.

However, the most frequent rating given for the impact on education and training was ‘neutral/mixed’. People's ratings for the impact on their relationship with their cared for person were also more balanced than for other categories, with 29% saying this was positive and 29% neutral/mixed, but 31% still saying the impact was negative.

Focus groups and interviews: icebreaker words

All the focus groups and interviews started with the question ‘What is the first word that comes to mind when you think about caring?’ The adults responded:

Compared to the adult carers, the young carers’ responses were generally positive and accepting of their caring role as just part of life. They explained that ‘caring is basically helping someone to get through life’.

Proportions of 55 carers indicating the impact of caring on each area of their life

	Physical health	Mental health	Employment	Financial situation	Education & training	Household tasks	Personal time	Relationship with cared for person	Relationship with others	Personal fulfilment
Positive impact	11%	11%	0%	4%	5%	9%	5%	29%	11%	16%
Neutral/ mixed	31%	20%	25%	27%	36%	22%	15%	29%	27%	24%
Negative Impact	47%	58%	55%	56%	34%	58%	67%	31%	49%	49%
No response	11%	11%	20%	13%	25%	11%	13%	11%	13%	11%

Focus groups and interviews: the impact of caring on physical and mental health

Several carers attributed their physical conditions to the challenges of caring, especially sleep deprivation or severe exhaustion and fibromyalgia. Others had experienced early menopause, weight gain, and physical injury:

> ‘I have fibromyalgia, due to the stress of looking after mum.’
>
> ‘I’ve had early menopause because of the stress.’

The most common mental health impact was **stress**, in one case to the point of ‘nervous breakdown’, followed by **fear and anxiety**, feelings of **depression** (described by one carer as being ‘heartbroken’), and loss of self-confidence. One carer with anxiety said that while her son was sectioned in hospital, she would still hear his voice – ‘This used to cause me to flinch’.

Their experiences suggested a **slow, everyday deterioration**:

> ‘My strength has dwindled.’
>
> ‘I was having a low-level breakdown in the background.’
>
> ‘The tiredness caught up with me.’

Some people said they pushed their needs aside as their cared for person’s **always came first,** ‘[I] need to stay well for my husband.’

A few carers of people with serious mental illness or early onset dementia struggled with **serious fears for their own safety** or that of their loved one:

> ‘I know that others worry about my safety when I am with him, but he would never hurt me…I bought a safe to put [all knives and sharp objects] in. I also placed my mirror strategically so that I could see what was happening behind me. This lasted for about 18 months.’
>
> ‘I used to get 3-4 hours’ sleep per night, as my husband was walking around the house banging and hallucinating…I was frightened because I did not know how things would evolve from one minute to the next. At one point, I was unable to go home [as he was threatening me with a knife].’

Physical health

Tiredness was the most often mentioned physical health issue, and it also contributed to mental health and employment challenges. A carer described the effect that tiredness was having on their income, stating, ‘I can't work as much as I would like to - I am too tired.’

Sleep proved challenging for some, particularly for those looking after individuals with dementia. A carer of an elderly parent with dementia explained their own broken sleep patterns, ‘Telecare equipment helps me monitor her activity, but I still have to soothe her and help her going back to bed.’

A carer explained that they had made a significant change to their sleeping arrangements to accommodate their cared for friend, ‘I have given up my bedroom and sleep on the couch in the sitting room, providing all her care.’

‘I do not find it easy to sleep.’

On a more **general** note, a parent carer commented, ‘[caring] has had negative impact on my health – [my son’s] lack of ability to adapt to change’ and a full time carer looking after a frail elderly person said, ‘taking on many responsibilities beyond me and suffering as a result - my health is beginning to decline as is my mental state.’

Mental health

A significant number of survey respondents described the negative impact of caring on their mental health. One stated, ‘I now have very bad depression, anxiety, stress and panic disorders,' and another described ‘extreme worry and depression over the past decade, ongoing’. A full-time carer commented, ‘I also feel isolated and depressed.’

Part of this anxiety was the **chronic stress** associated with the cared for person’s health. Many carers were ‘on 'high alert' waiting for a crisis’. One carer described the situation, ‘unpredictable night behaviour and risk of wandering in my mother require that I have to be in a state of constant alert’.

Parent carer respondents suffered high anxiety levels due to worry about the future.

Personal time

67% of respondents rated the impact of caring on their personal time as negative or strongly negative, giving it the most negative response level of all the categories.

Constant requirements to monitor the cared for person and anticipate their needs prevented some carers from having any time to themselves. A parent carer of two adult children explained, ‘I am a 24-hour carer to two children, who both have disabilities and one of which needs watching at night. This means I have no time to myself’. Another carer of a person with learning disabilities said, ‘I don't have much personal time, I would like to participate in activities, but she does not engage.’

‘I'm constantly worrying about her and her future, which has affected my mental health.’

Dementia carers provided particularly stark comments, with one saying ‘Caring for someone with dementia is all consuming - there is no other life’, and another describing the relentless nature of the commitment, ‘I have not had a life now for 6 years since my husband’s diagnosis.’

Referring to a need to **manage time carefully**, a carer of an elderly mother said, ‘I have to plan events one year in advance to ensure that hospital and doctors' appointments are covered first and foremost. This can be challenging and time consuming, which puts a lot of pressure on me.’

Several carers clearly confirmed that **taking holidays was not an option**. Referring to their child’s anxiety level, another stated, ‘I haven't been on any holidays for a long time.’ Another parent carer commented, ‘I have never had a single day off in 30 years, because I am doing this alone. This has left me with no time to myself.’

‘I do take time out for myself, but seldom relax and enjoy myself as am constantly worrying about the children and their futures.’

Referring to a **lack of suitable opportunities for young carers,** an 18-year-old caring for their parent commented, ‘Time to myself is sometimes limited. Lack of getting out - bring back young carers’ youth clubs.’

Even if they were able to spend time away from their cared for individuals, some carers referred to **anxiety that impacted on the quality of this time**. One parent carer said, ‘I do take time out for myself, but seldom relax and enjoy myself as am constantly worrying about the children and their futures', and a carer to both a learning disabled child and a parent found, 'There's no time for myself; I can't go out to places on my own as I'm worried about the others.' The time pressures also meant carers spent their respite 'catching up on financial, legal and day to day tasks.'

Relationship with the cared for person

More carers (29%) rated the impact of caring on the relationship with their cared for person **positively**, compared to any other area. One carer explained, 'I have learned to love more and care more', whilst another described how 'I spend more time with relatives I am caring for, so have got closer to them.'

However, 31% of carers still rated the impact in this area as negative. A carer of an elderly parent with dementia struggled with the **loss of control** associated with their mother's condition, explaining, 'I needed advocacy for three DOLS [Deprivation of Liberty Safeguards] assessments, but was never given this. I never received a report from the three DOLS assessments that took place.'

'I have learned to love more and care more.'

Another carer voiced **frustration** at the lack of support given and consequent impact on their relationship with the cared for person, 'Being a friend and not living with her has been challenging, and authorities just give more and more demands.'

Relationships with other people

Carers described pressure on personal relationships caused by a **lack of personal time.** A part time carer of an elderly parent in another location commented, 'Time is so precious but often given to others at detriment to my relationship with my husband, family and friends', and another 'I spend at least half a day every weekend supporting them, which impacts my ability to go away/see friends and other family during weekends'.

'I cannot stay overnight at my girlfriend's house - only 14 nights per year through respite.'

For some, a lack of personal time was combined with having to be constantly present – a person with a severely physically disabled daughter commented, 'I find that I have practically no social life as I can't leave my daughter alone'.

'As a family, we have become isolated. I know a lot of people, but do not have any really close friends and can feel desperately lonely at times'.

Some people also described the **long-term impact of caring on their support network**. A full-time carer to two adult children with learning difficulties explained that the lack of time to herself had 'left us with no family or friends to help' and another in a similar situation said their family had become 'isolated'.

Focus groups and interviews: the impact of caring on other relationships

Some people struggled with **social isolation**, especially when they were caring for someone with a mental illness or dementia:

> ‘Our neighbours were afraid, as my husband suffers from bipolar.’

> ‘When I was looking after my husband, I couldn’t ever go out.’

They also worried about the **knock-on impact on other family members** of distressing caring experiences:

> ‘The police had to come, as she [cared for daughter] had locked herself in the bathroom...After this had happened, my son said that no one had asked him how he had felt about the experience.’

Personal fulfilment

Some carers explained that the **time commitment** associated with caring had limited their ability to feel personally fulfilled. One carer noted there was, ‘no time to develop other areas in my life - it's all consuming care’, with another stating, ‘I cannot achieve personal goals as I don't have the energy or time. I cannot travel,’ and a third commenting on a ‘lack of time for friends, own interests.’

Others noted the impact that their caring roles had had on their connection with their faith group, with one explaining, ‘I was an avid church goer, who played the organ every Sunday and had an active social and leisure life’.

‘My life as an artist has totally disappeared as I am a 24-hour carer’.

Employment

Several carers stressed **limitations to their ability to work**, due to their caring commitments. One commented, ‘I can't work as much I would like to - my mum would become unsettled’, whilst another noted, ‘I have had to change my working hours to free up half a day per week to support my parents’, and a third, ‘It is extremely difficult to juggle my own family life, work life and caring role’. Another carer’s full time commitment prevented them from getting any employment at all, ‘I can hardly go anywhere, so I cannot work and don't receive help from anywhere.’

A **self-employed carer** explained the challenges associated with working and caring, ‘It has impacted on extra pressure when working, stress at not having enough time and energy to get everything done and on finding new work, as something happens and you end up dealing with that all-consuming task rather than finding the next piece of work.’

‘Working full time and caring is really difficult. My employer is flexible but I could not change jobs or go for promotion. I fear having to give up work which would have a hugely negative impact personally and financially.’

On a positive note, another carer found the **career coach support service** provided by SLaM helpful, ‘I am getting some support from Work Well to try and access employment that won't negatively impact my mental health, and that fits in with my caring responsibilities.’ (As of March 2019, this service is no longer open for new referrals as funding from the EU and Big Lottery is ending).

An **older carer provided a different perspective** by noting, ‘As I am retired, the time is not too much of a problem. Feels much better than when I was trying to work and care.’

Financial situation

Referring to the lack of support provided by the statutory services and the **financial pressure** this had created, a carer commented, ‘The DWP [Department of Work and Pensions] has not reinstated my Carer’s Allowance since I stopped part time work last March. I continue to complete all forms they ask me to fill out and was told this week my case is dormant, but they didn't know why. I have had no financial support from DWP in 10 months. This is not fair, but I still have to be a carer regardless of any payment. No help with fighting DWP, plus too tired.’ For more information on the financial impact of caring, see the section on Carer’s Allowance (page 20).

Focus groups and interviews: the impact of caring on financial situation

One carer became trapped in a situation where, because they worked, they did not qualify for financial support. However, to continue working they had to **pay for private care**, while cutting down their hours. As a result, they went into debt:

> ‘I incurred rent arrears of about £1,000...I used to use credit cards to pay carers and rent and was £2,000 in debt.’

Feeling abandoned

Some carers expressed their sense of feeling alone with the heavy responsibility they held. On resignedly said, ‘The system just lets you get on with things.’ Another described their situation candidly, ‘Being a caring and dedicated personal friend who simply could not see her suffer, only to find myself alone, taking on many responsibilities beyond me and suffering as a result. I do feel that I have been left on my own.’

Young carers' focus group: the impact of caring on young people

Several young people had experienced an **unstable or changing home life** due to their cared for person's condition:

> 'My mum and I used to live at my nan's house. I didn't have to worry...but when she got diagnosed with depression, it all changed.'
>
> 'There were leaks...the Council found [another] house to move to but we'd have to move schools.'

A few young carers had also been **bullied** due to their cared for sibling's condition, which meant their 'school life had changed a lot.'

The young carers' **schoolwork**, as well as their **friendships**, had also been impacted by a **lack of personal time:**

> 'There's not enough time [to see friends], as I have to do stuff.'
>
> 'I used to be in the top set [at school] but have had to move down a set, as I don't have enough time.'

For others, caring had a more severe impact on their social confidence:

> 'You don't want to talk to anyone. You don't want to go out.'
>
> '[Caring has affected] my social life. I can be more introverted; I don't go out with people so much.'

However, for several participants, caring was not portrayed as the most important or most difficult thing in their lives. They placed it in the background of, or alongside, other childhood troubles. For example, they moved rapidly from talking about the impact of caring to talking about how their friend had moved away, their dog had died, or they were moving to secondary school.

We also asked the young carers what was good about being a carer, and if they had learnt anything new. They mentioned **responsibility, and knowing more** than their peers:

> 'We might have our mental state broken down, but we know more.'

Personal characteristics

We asked respondents if they felt they had any characteristics that influenced their experience as a carer, and how. This was a free text question, but we gave examples from the legal protected characteristics, including age, gender, disability, or ethnicity.

23 people (42%) did not note any relevant characteristics, and two more said they did not understand what we were asking.

Characteristic	Number of mentions
Age	7
Disability/long-term illness	5
Mental health issues	2
Migration status	1
Religion/faith	1
Gender	1
Other	5
No influential characteristics	8
Did not understand question	2
No response	23
Total respondents	**55**

The most commonly mentioned influential factor was **age**. For most people, age had a negative impact, as caring made them feel more 'tired' and 'drained' as they got older. One person said, 'I am not getting any younger and it is difficult to run after him when I take him out.'

On the other hand, one person said that age and their children now being grown up has a positive effect as it made it 'more possible' for them to be a carer.

The other most common characteristic that influenced people's experiences of caring was **disability or long term illness**.

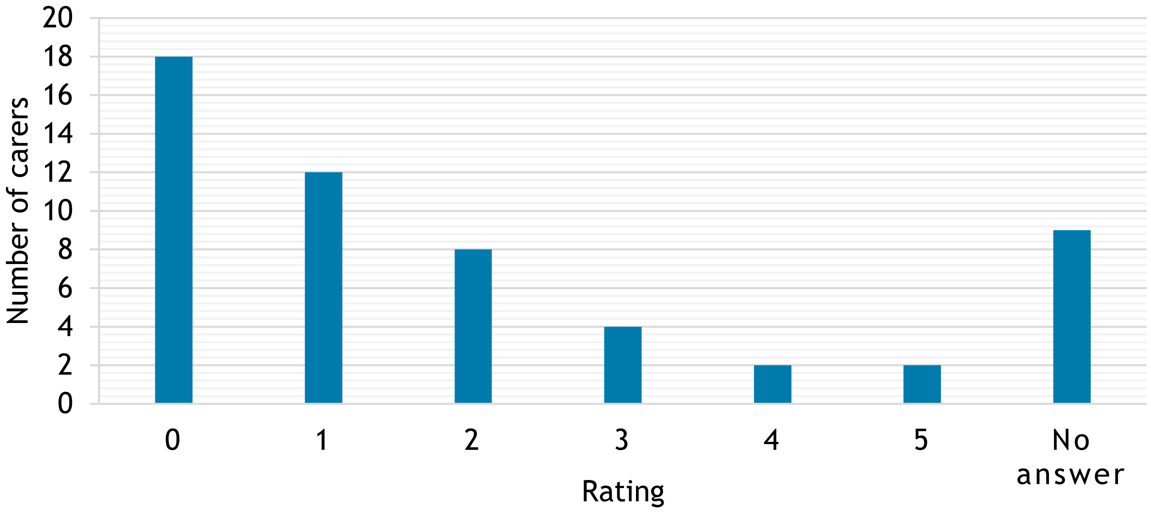
'Because I also have a disability… it affects me in every single part of life.'

Another person said that their **faith** had a positive impact on their caring experience as it helped them 'sustain what [they are] doing'. However, note that someone else mentioned elsewhere that their caring responsibilities prevented them from practising their faith, 'I would like to attend church every Sunday...which enables me to link and mix culturally'.

Finally, one woman described the impact of **gender** on her experience, 'There is still a gender bias on occasion, to show extra authority I've had to bring my husband in a suit as a man in a suit is often taken more seriously.'

How well supported do people feel as carers?

We asked people to rate how well supported they felt as a carer, where 0 meant 'not at all supported' and 5 meant 'totally supported.' Over half of carers (55%) rated how well supported they felt at 0 or 1.



Focus groups and interviews: general view of support available to carers

Overall, **finding and arranging support** was often a highly stressful experience, involving navigation through a 'disjointed' system, and continually chasing or pushing services, making 'numerous phone calls', all interspersed with long waits and periods of silence:

> 'You have to ask and ask and ask...doesn't this take it all out of you?'

This was one factor contributing to feelings of **distrust** among carers:

> 'Service providers...take advantage of the fact that carers are too busy with their responsibilities to complain or fight for support.'

Focus groups and interviews: the contribution of carers to society

There was a strong sense that carers were **extending the life** of their cared for person, by providing something that no one else could or would:

> 'My mother and sister's lives would have been shortened if we didn't help, because they would not get the care they need.'

> 'He would be dead by now if I didn't keep him living, rather than existing.'

This responsibility led into anger, and a sense that their contribution and sacrifice was **not being appreciated** by the government:

> 'We've got no lives and we save them billions.'

> 'Without the support carers provide, the person in need would depend solely on the government. Many of us give up our lives to care.'

Carers' suggestions for change

34 respondents provided suggestions for further support they would like to receive, or anything that would improve their experience as a carer.

Recognition and attitudes

Five people said they felt there was a need for improved **attitudes and understanding** towards unpaid carers – one said, 'Someone actually giving a s**t about the hard work we do for free would be nice' and another requested 'Honesty and integrity. That is the only support I need.'

'I feel they don't truly understand what carers have to face.'

One of these people suggested **formal recognition** of carer roles, such as an ID card, partly to raise the profile and status of caring, and partly as a practical measure – 'to make representations to third-parties easier.'

Information about available support

Four people requested better **information about available support** (for themselves or their cared for person) - 'More information about [how] the health and social care services work and apply to individual scenarios would save one having to self-inform.' This included around transition from children's to adults' services.

'Provide greater signposting to those [services] that already exist — even for an otherwise articulate and enquiring carer it can be surprisingly hard to ask and hard to find out.'

Training for carers

Five people mentioned **training** for carers and information about their loved one's condition, for example dementia and how to communicate with someone with dementia. One person specified a ''How-to' carer's pack (available at the first point of contact) to which a 'dossier' of background information on the cared for person's illnesses and condition can continue to be added to by the clinical-welfare team etc.'

General, emotional and social support for carers

People mostly asked for **general carer support**, and made wide-ranging suggestions around ways to provide this. This included:

- Carer events, groups and organisations, including social activities to bring carers together, young carers' groups, and mutual support.
- Befriending
- Regular visits 'to see how we are, to see what we could have…someone to care for me as the carer'
- A key contact person - 'There are too many experiences and it's overwhelming when you're tired, so you just keep going on your own'
- Regular carers' physical and mental health checks
- Complementary therapies – 'I'd like to think we've earnt them :-)'

On a related note, several more people asked for 'a break' or **respite care,** including overnight or for a holiday. Further carers asked for **activities, such as day centres, for their cared for person** – to provide respite for the carer, as well as stimulation for the cared for person. One of these carers highlighted in particular a gap for people transitioning into adulthood, 'My son has left college due to his age according to Education. I have been looking for activities to occupy him without support from Social Services.'

Some families needed **adjustments to the physical environment**. A few mentioned housing, for example wanting their cared for person to go into supported housing, or to have a garden so that they could go outside. Others asked for more support to go out, including transport and 'help with toileting outside the home; places to go that have the equipment we need.'

A few people asked for **more financial support** and a fourth person suggested **discounts for carers,** particularly at hospital outlets but also in the wider community, 'We may not be NHS staff but are 'doing the job' of a nurse-escort and saving the NHS plenty of money :-) ...St John's Ambulance volunteers, after all, qualify for discounts.'

Coordination

Several carers asked for **support to navigate the system and coordinate their cared for person's care** – 'Sorting out these practicalities would make everything else less difficult.' Some of these people suggested a single point of contact, such as a social worker – 'Someone who could practically help with the maze of authorities both medical and benefits, housing support, DWP, PIP etc.' Another said this was about better organised individual services such as GPs and hospital appointments. One carer explained that information sharing between services was a barrier to coordinated care, 'The Doctors are supposed to be coordinating his treatments between King's and Guy's but they physically can't even read each other scans between the two hospitals… even though we keep being told they can. GP office completely out of the loop.'

Changes to direct support for the cared for person

For many people, the most needed changes mentioned were around **professional care provided to their cared for person**. This concerned a variety of services:

- Provision of care at home, or money to pay for this (one carer felt this should come from the NHS due to the nature of their relative's condition)
- More district nursing
- Better continence services
- More access to hospital appointments
- More choice of schools and colleges for autistic people
- 'Earlier intervention'
- Different services 'to respond quicker to meet friend's needs as I feel 3 months is far too long for replies and still waiting which causes anxieties.'

One of these people wanted a broad 'whole family **assessment**' to set up the appropriate support for their children.

4 people mentioned wanting **more involvement in decisions about care -** for one, this meant 'I would like Direct Payment so I can plan how I need and can use the service.' For two, this was because their relatives had been removed from the family and placed in residential care against the wishes of the family. Whether or not this was the right decision for the cared for person, carers may need more support in such scenarios – one wanted advocacy and another felt they had been misrepresented and that 'I get no support from Social Services.'

Appendix 1: The carers and the people they care for

Overall, 63 unpaid carers responded to the survey. 8 responses were excluded as they gave no responses beyond the initial demography. 55 responses were analysed.

This was a qualitative survey not aiming to be representative of the entire population of carers. However, the respondents and their cared for people were diverse enough in their needs and relationships to help us build an early picture of the landscape for unpaid carers in Southwark.

In total, our 55 carers provided support to 78 people (see page 11). We asked for detail only about the first two cared for people (i.e. 72 people).

Locations of carers and their cared for people

All but three carers were Southwark residents. The large majority of cared for individuals were also based in Southwark.

	Carer	First cared for person	Second cared for person
Living in Southwark	51	42	13
Living outside Southwark	3	4	3
Not disclosed	1	9	1
Totals	**55**	**55**	**17**

Relationships between the carers and cared for people

The carer respondents were looking after a wide range of people, with the largest categories being parents, children under 18 and adult children.

Cared for person's relationship to the carer	First cared for person	Second cared for person	Total cared for people	% of 72 cared for people
Friend or neighbour	3	1	4	6%
Spouse or partner	8	2	10	10%
Son or daughter	14	6	20	28%
…under 18 years	7	3	10	14%
…18 years or older	7	3	10	14%
Sibling	2	0	2	3%
Parent	23	7	30	42%
Other	2	1	3	4%
Not disclosed	3	0	3	4%
Totals	**55**	**17**	**72**	**100%**

Age of carers and cared for people

Whilst carers from a broad range of age groups responded to the survey, we did not receive any responses from young carers under 18 years of age. (We later conducted a focus group with eleven young carers).

Age of carer	Number of carers	% of 55 carers
Under 18	0	0%
18-35	6	11%

36-64	38	69%
65+	10	18%
Not disclosed	1	2%
Total	**55**	**100%**

The cared for people were also diverse in age, though more than half were older people.

Age of cared for person	**First cared for person**	**Second cared for person**	**Total cared for people**	**% of 72 cared for people**
Under 18[1]	7	3	10	14%
18-35[2]	7	4	11	15%
36-64	7	2	9	13%
65+[3]	30	8	38	53%
Not disclosed	4	0	4	6%
Totals	**55**	**17**	**72**	**100%**

[1] All of these were the children of the carers.
[2] All but 2 of these were the children of the carers.
[3] The majority of these were the partners or parents of the carers.

Cared for people's conditions

Categories of condition	**First cared for person**	**Second cared for person**	**Total cared for people**	**% of 72 cared for people**
Physical ill-health or disability	35	11	46	64%
Learning disability and autistic spectrum disorder (ASD)	13[1]	4	17	24%
Mental ill-health	16	7	23	32%
Dementia	16	3	19	26%
Frailty or old age	20	6	26	36%
Not disclosed	3	1[2]	4	6%
Total number of people	**55**	**17**	**72**	**100%**

[1] One further person also specified that their cared for person had autism, but did not tick the LD/autistic spectrum column
[2] But specified 'behavioural problems'

At least 48 (67%) of the 72 cared for people had more than one condition (this is based on people having conditions falling into more than one category, as well as a few cases where people gave optional detail about multiple conditions in the same category). This suggests the complexity which many carers need to manage.

Living arrangements

64% of cared for people lived with their carers. 34 carers lived with a least one of the people they cared for and seven lived with two.

	First cared for person	**Second cared for person**	**Total cared for people**	**% of 72 cared for people**
Living with carer	33	13	46	64%
Not living with carer	14	3	17	24%

Not disclosed	8	1	9	13%
Totals	**55**	**17**	**72**	**100%**

Our adult focus group and interview participants and the people they care for

Main cared for person lives...	Number
...in a care home (but may previously have been at home)	5
...with the carer	4
...independently	2
...in hospital while a suitable care home is sought	1
Total	**12**

Cared for person's relationship to the carer	Number
Adult son or daughter	5
Parent	4
Partner	3
Total	**12**

Categories of condition	Number of cared for people
Dementia	4
Learning disability and autistic spectrum disorder	4
Mental ill-health	3
Frailty or old age	4
Physical ill-health or disability	4
Not disclosed	1
Total	**12**

Seven of the cared for people had more than one condition.

Our young focus group participants and the people they care for

All of the participants were aged between 8 and 12, and four were boys and seven girls. We did not ask participants for any personal details, but discussions revealed the young carers were all caring for parents, who mostly had depression and other mental health issues, or their siblings, primarily with learning disabilities, autistic spectrum disorders, attention deficit hyperactive disorder (ADHD) and obsessive compulsive disorder (OCD). One carer had recently dealt with the death of a sibling.

Appendix 2: The survey questionnaire

Healthwatch Southwark promotes the voice of patients and the public to improve health and social care services. We want to find out about the experiences of unpaid carers in Southwark, and what more could be done to support them.

A carer is anyone who looks after somebody who needs regular help with their daily life because of their illness, frailty, disability, a mental health problem or an addiction, and cannot manage without the carer's support. This does not include parenting care without these additional challenges. The care given is unpaid. The carer might be an adult or a child.

Do you fit this description? If so, we would really appreciate your feedback through this anonymous survey. Once completed, please return it to:
Healthwatch Southwark, Cambridge House, 1 Addington Square, London SE5 7JZ.

The survey is also available online at.

About you

1. **Please specify your age group.**
○ under 18 ○ 18 - 35 ○ 36 - 64 ○ 65+

2. **Do you live in the borough of Southwark?**
○ Yes ○ No (please state your borough, and continue with the survey if any of the people you care for live in Southwark)
____

The people you care for

3. **Please tell us about the person you care for. If more than one, please tell us firstly about the person for whom you provide the most care.**

Their relationship to you (e.g. parent, sister, friend): ____________________________
Their age: ○ under 18 ○ 18 - 35 ○ 36 - 64 ○ 65+
Do they usually live with you? ○ Yes ○ No
Do they live in the borough of Southwark? ○ Yes ○ No ○ Don't know
Do you share care for them with another unpaid person?
○ No ○ Yes, but I am the main carer ○ Yes, someone else helps equally/more

4. **Does this person have any of the following?**

☐ physical health condition(s) or disabilities (please specify below)
☐ learning disability or autistic spectrum disorder
☐ mental health condition(s) (please specify below)
☐ dementia
☐ general frailty or old age

Details: ____

5. **If you care for other people, please tell us about the next person here. If not, move to question 8.**

Their relationship to you (e.g. parent, sister, friend): ____________________________
Their age: ○ under 18 ○ 18 - 35 ○ 36 - 64 ○ 65+
Do they usually live with you? ○ Yes ○ No

Do they live in the borough of Southwark? ○ Yes ○ No ○ Don’t know
Do you share care for them with another unpaid person?
○ No ○ Yes, but I am the main carer ○ Yes, someone else helps equally/more

6. Does this second person have any of the following?

☐ physical health condition(s) or disabilities (please specify below)
☐ learning disability or autistic spectrum disorder
☐ mental health condition(s) (please specify below)
☐ dementia
☐ general frailty or old age

Details: ____

7. Do you care for anyone else? Please specify how many more people. __________

The care you provide

8. Thinking about all the people you care for, what types of support do you provide?

☐ personal care (e.g. washing, dressing, toileting, feeding)
☐ household (e.g. shopping, laundry, cleaning, cooking, paying bills)
☐ nursing (e.g. bandages, catheters, giving medicines, monitoring blood sugar)
☐ mobility assistance (e.g. to medical appointments, social activities)
☐ care coordination (e.g. making appointments, following up with services, communicating with professionals)
☐ emotional
☐ other (please specify:) ______________________________

9. Thinking about all the people you care for, how many hours per week on average do you think you spend providing care? ____________________

10. Overall, how well do you think professionals involved with your cared for person communicate with you and keep you updated? Think about all sorts of services from carers, to GPs, district nurses, social workers, physiotherapists, clinics, or staff caring for the person during a hospital stay.

○ Very well ○ Quite well ○ Neither well nor poorly, or mixed ○ Not very well
○ Not well at all

Any comments? (e.g. examples of services that communicate well or poorly) ____________
____
____

Your entitlements as a carer

11. If you regularly provide a substantial amount of care for someone, you are entitled to a carer’s assessment of your own, separate from that of the person you care for, to see what you need and what might help you with your caring role.

Have you had a carer’s assessment completed for you?
○ Yes, by Southwark Council ○ Yes, by another council ○ No ○ Don’t know

12. Do you have any comments about the experience of the assessment, or its outcome? ____________________________________

____

____

13. Are you currently receiving Carer's Allowance?
○ Yes ○ No

14. Whether you receive Carer's Allowance or not, are there any costs involved in being a carer that you pay for yourself (i.e. aren't covered by the allowance)? Please list the items and estimate the amount you are spending per month, or write 'none'.

____

____

____

The impact of being a carer on your life

15. What impact has your carer role had on different areas of your life? Please tick one rating box for each area.

Area of life	Strongly positive impact	Positive impact	Neutral or mixed impact	Negative impact	Strongly negative impact
Your physical health					
Your mental health					
Employment					
Financial situation					
Education/training					
Household management/day to-day tasks					
Time to yourself					
Your relationship with your cared for person					
Your relationships with other people					
Personal fulfilment					

Please explain how you have been impacted in these areas of your life, and/or note any other important areas of impact: ____

____

____

____

____

16. Do you feel you have any characteristics which impact on your personal experience as a carer, and how? These might include your age, gender, gender reassignment, sexual orientation, marriage/civil partnership, pregnancy/maternity, disability, ethnicity, religion/belief, or asylum/migration status. ________________________

____

____

____

External support you receive as a carer

17. Do you receive support as a carer from any groups (e.g. at a hospital) or voluntary/charity/community organisations?

○ No ○ Yes

If yes, please state which groups: ____

____

18. How does this help you? ____

____

19. When did you last have a respite holiday away from your carer responsibilities, and how long was it? Please specify month, year and duration. ______________________

____

20. Who looked after your cared for person when you took this holiday?

☐ none – they coped with their usual services while I was gone
☐ relative
☐ friend
☐ extra support from a home care service
☐ care home
☐ other (please specify:)____

21. How was the respite care? Did you have any concerns? ______________________

____

____

22. On a scale of 0 (not at all supported) to 5 (totally supported), how well supported overall do you feel as a carer? ____

23. Please explain any further support you would like to receive, or anything that would improve your experience as a carer. ____

____

____

____

Thank you for taking part in this survey.

Your anonymised responses will be included with other findings in a report. We will publish the report on our website (www.healthwatchsouthwark.co.uk) and share it with those who monitor, commission and provide services in Southwark.

If you would like to receive a copy of the report, please provide your contact details below. We will separate this from your survey responses when analysing the results. *For our full privacy statement, visit* https://healthwatchsouthwark.co.uk/content/privacy-policy.

Name: **Email address:**

Postal address:

Appendix 3: The focus group and interview questions

Adult carers

Ice breaker: Write down the first word that pops into your head to describe your life as a carer – each member then explains why they chose this word.

[Ask if they would like to say which borough they live in and who they care for (e.g. parent, sibling), but only if they are comfortable with disclosing this.]

Questions:

1) Could you tell us about experiences you may have had with Southwark Council Adult Social Care or other statutory services *supporting you as a carer* and how this was for you?

   Have you had a carer's assessment? Did this result in access to financial support?

2) Could you tell us about how caring may have *impacted* on you as a person? (e.g. your mental health, any long term condition you may have, your social life, work life/finances).

   Have you had any respite breaks during the past 6 months? (How long for? How difficult is this to arrange? How helpful is respite for you?)

3) What do you think about the support that is out there for carers in Southwark generally? (e.g. quality of it, voluntary and community groups, anything at the hospitals?

   Is there enough support? Where would you get information *about support (e.g. your GP)?*

4) How do you think carers contribute to the community and society as a whole? (e.g. can you reflect upon the *value you add* to your cared for's life and the lives of others, also the *value and support you give to services* in Southwark.)

Young carers

Ice breaker: Please tell me the first word that pops into your head to describe your life as a carer. Explain why you have chosen this word.

[Ask if they would like to say which borough they live in and who they care for (e.g. mum, dad), but only if they are comfortable with disclosing this.]

Questions:

1) Could you tell us about how caring may have *impacted* on you? (e.g. your social life, school, physical and mental health. Do you have any long term conditions yourself?). Do you remember your life before you became a carer?

   Have you had any respite/holiday breaks in the past 6 months? (How was this arranged? How long for? How did you feel afterwards?)

2) What do you think about the support that is out there for young carers in Southwark (your school, GP, Imago/the Council, any voluntary and community groups)? Is any of these particularly helpful to you?

   Is there enough support? Where would you get information *about support?*

3) Tell us what's good about being a carer? What have you learnt and what skills have you acquired?

   Do you think these skills will help you in your own life (eg: when you go out to work)?