

Report on the Healthwatch Wandsworth Carers' Survey

Background

Healthwatch Wandsworth launched a survey to gain insight into what it is like to live as a carer in Wandsworth, including issues around their own health and what support they need to help them live well whilst caring for a family member or friend. Carers have a central and important role in the health and care of the people they look after and they often tell us about the additional challenges and health inequalities they face which impact on their own health and quality of life.

Although we conducted a survey in 2016 to contribute the views of carers to the development of Wandsworth Council's [Carers' Strategy](#) we again wanted to measure the experiences of carers in Wandsworth two years on. In this new survey we encouraged carers to share their views with us on the support that is available and what more can be done to improve support.

The consultation was open from 5 July 2018 until 24 January 2019.

Findings

We advertised the opportunity to participate on our website and social media and circulated it to our local contacts. We also took the survey to outreach sessions in Wandsworth at many community-based organisations and events including:

- Wandsworth Carers' Event at Wandsworth Town Hall
- Carers' week stall at Southside Shopping Centre
- Focus groups with carers at Wandsworth Carers' Centre, including carers supporting people with substance misuse, autism and learning disabilities.
- Baked Bean Theatre Company
- The Alzheimer's Society Dementia Hub
- Young Carers & Carer Champions at the Aspire Centre

In total, 51 carers across a range of ages completed the survey. They support people with a variety of health needs.

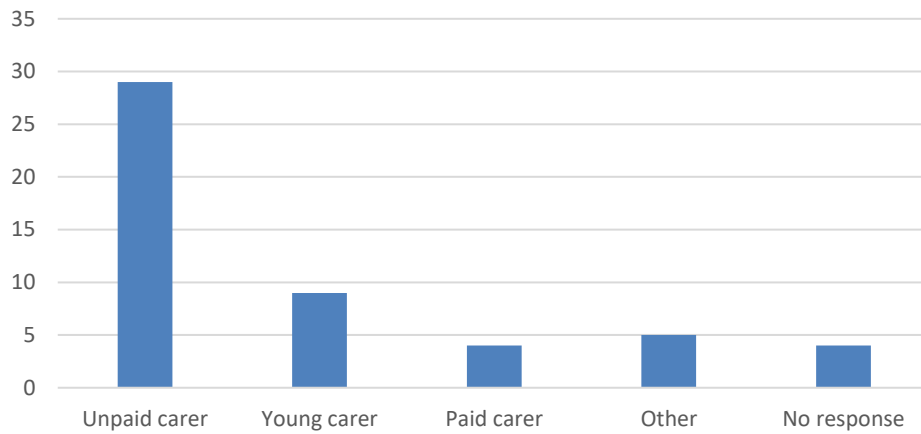
A mixture of open and closed questions were used to draw out people's experiences, thoughts and suggestions, through which we were able to draw conclusions about the experiences of carers in Wandsworth.

About our respondents

Our first questions were designed to understand more about the carers we spoke to.

Question one: Are you a paid carer, unpaid carer, young carer or other?

Most of our respondents were unpaid carers and almost a fifth were young carers. Those who answered 'other' didn't provide any further details, except one person who described themselves as a 'mother/carer'. The charts below show the responses to this question.



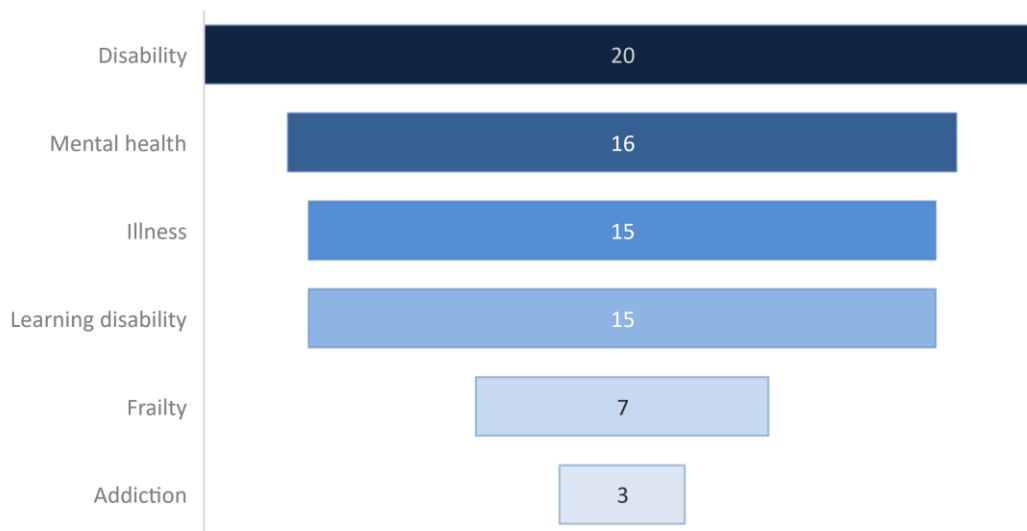
Type of Care	Percent (number of respondents)
Unpaid carer	57% (29)
Young carer	18% (9)
Paid carer	8% (4)
Other	10% (5)
No response	8% (4)

We asked people who they care for.

People told us that they care for different family members: children, spouses, siblings, parents, parents-in-law and other relatives.

We asked people why the person they care for needs help.

Many people told us that there were multiple reasons why the person they care for needed help. As shown in the charts below, disability was the most common answer to this question, closely followed by mental health, which may in some way reflect that physical health needs can be accompanied by, or have an impact on, mental health.



Reason for needing help	Percent (number of respondents)
Disability	39% (20)
Mental health	31% (16)
Illness	29% (15)
Learning disability	29% (15)
Frailty	14% (7)
Addiction	6% (3)

We asked people how many hours they spend caring per week.

Most people told us that they care for their relative **24 hours a day or full time**.

Time spent caring	Percent (number of respondents)
24h per day (or 120+ hours per week)	24% (12)
Full time (30+ hours per week)	39% (20)
10 to 24 hours per week	16% (8)
Less than 10 hours per week	8% (4)
Not specified or variable	8% (4)
No response	6% (3)

Some people highlighted that the time spent caring is difficult to quantify.

“Emotional care is hard to quantify in hours per week.”

“For a mental health carer this is not a good question. We are “on call” 24/7, but not necessarily providing direct “care”. This is not well understood.”

We also asked people how long they have been carers.

The table below illustrates that different people had been caring for varying lengths of time, **although just under half (24 respondents, 47%) have been carers for more than five years**.

Years spent caring	Percent (number of respondents)
50+	2% (1)
40+	4% (2)
30+	6% (3)
20+	10% (5)
10+	10% (5)
5 to 10	20% (10)
Less than 5	18% (9)
Since birth	10% (5)
Other	10% (5)
No response	12% (6)

Carer’s assessments and carer’s allowance: accessing support

Wandsworth Council is responsible for assessing the support needs of carers and are a key route for carers to get that support.¹

Question two: Have you requested or been offered a carer’s assessment in the last 12 months?

Less than half (21 responses, 41%) of the carers that filled out the survey told us that they had requested or been offered a carer’s assessment (see table below).

Carer’s Assessment	Percent (number of respondents)
Yes	41% (21)
No	55% (28)
No response	4% (2)

¹ Social Care Institute for Excellence (2019), The Care Act: assessment and eligibility [Online]. Available at <https://www.scie.org.uk/care-act-2014/assessment-and-eligibility/>

We then asked people if they had, what services they had found helpful or would find helpful.

Among those who had a carer's assessment, a few people told us that it was helpful, but many people told us that they thought it was not.

The main concerns people told us about were:

- Inadequate financial assistance
- Being told that they were ineligible for services or support, and not being signposted to other information and support
- Staff knowledge about the assessment, entitlements and local services could be improved
- That assessments are not always carried out by doctors or social workers
- Waiting times to get an assessment
- Getting more information as a situation changes over time

“There are long waiting lists with social services for the carer's assessments”

“Sometimes they start the carer's assessment, but the person from social services starts and doesn't finish, then the person leaves and they have to find someone else. The social worker doing my assessment kept falling asleep on and off during his visit. The social worker had to call back multiple times to check he had asked certain questions.”

“There's a lot of information that social workers (especially new ones coming in) don't know.”

“It was pointless - waste of time. Asked what I wanted to get out of it. Didn't find out what is available. Apparently, I am doing all the right things so they can't help me. Council are financially depleted so not much available. Think there are small bits of money for some things but not suggested.”

“E.g. for the carers' grant (the council-run grant with a £250 set amount), social workers tell carers to speak to the Carers' Centre, but the Carers' Centre doesn't issue the grant - the council does. The Carers' Trust offers a grant up to £300, which has to go through the Carers' Centre.”

“I have been trying to get in touch with the council for 6 months and can never get hold of anyone.”

“I have been assessed. Tried for 2 years and only just done by a person at a day care centre, not a social worker.”

“I received a carers assessment - about 2 years ago. After that my husband's health deteriorated, and he required daily care. I thought that social services were meant to review carer's assessments - this did not happen to me, and there was no point in asking for a further assessment - it would just have been a waste of time. Earlier this year my husband died.”

“I asked for a carer's assessment. I would like a Dr to carry out the assessment, not a nurse. Wandsworth carer's centre is useful. I would like more help about the next stage of my son's caring and especially do not need the added stress of a PIP appeal.”

“I was only eligible for a small amount. However, I was advised to contact charities for assistance/ Financial assistance before the council would help.”

Question three: Are you receiving a Carer's Allowance?

Most people told us that they were not receiving a carer's allowance (16 respondents, 31%). This is interesting given that most people had said that they are a carer 24 hours a day or full time. This suggests that most of the financial costs of providing care for relatives is taken on by the carers themselves.

Carer's Allowance	Percent (number of respondents)
Yes	31% (16)
No	67% (34)
No response	2% (1)

Among those receiving a carer's allowance, some people told us that the application process was "fairly straightforward" while others said that it was "not easy" and that it "took a while". This suggests that some people would benefit from additional support when applying for a carer's allowance.

"If you're a pensioner (claiming state pension), you don't get a carer's allowance. You get a little bit on top of the pension (e.g. £15)."

"It is not easy. I have tried with the access team over the phone. One said I am not entitled to a care assessment."

"I got help from HAIL with the application process."

One carer told us that they were offered an appointment after their application for a face-to-face assessment. But they were offered an appointment in Brent - even though they live in Wandsworth. They had to call and get the location corrected and when they arrived for the assessment, they were asked the same questions repeatedly, which they found stressful (something that other carers present at the group session agreed with - stressful and repetitive).

Support services

Question four: Have you received information and advice on the support services that are available for carers?

Most people told us that they had received information and advice about support services for carers (30 respondents, 59%). However, over a third (19 respondents, 37%) told us that they had not received any information or advice. This suggests that more could be done to ensure that all carers have access to information about support services.

Information and advice about support services for carers	Percent (number of respondents)
Yes	59% (30)
No	37% (19)
No response	4% (2)

Many people told us that Wandsworth Carers' Centre is a useful service for carers.

"Carers' centre has been a rock of support. It's a shame they can't have more funding because they understand us."

People told us about other forms of support that are, or would be, helpful for carers:

- Respite care
- Bluebird Care Wandsworth (homecare)
- Carers' Events
- Carers' newsletters
- Assistance with application for carer's allowance
- Family Action Wandsworth
- Massage

People told us **about challenges accessing mental health services** after being referred from Wandsworth Carers' Centre.

“They [Wandsworth Carers' Centre] are excellent and referred me to a councillor straight away. Dr offered me IAPT [Improving Access to Psychological Therapies]² and I was 69th on waiting list - 4yrs.”

“Carers' Centre offers useful support of various kinds. There is not enough contact of liaison with the mental health services, who have an important role - or SHOULD have.”

Question five: As a Carer, have you received any training or information about the health condition of the person you are caring for?

Most people (32 respondents, 63%) told us that they had not received information or training about the health condition of the person that they care for. This suggests that there is an unmet need for more information and training for carers.

Training or information about health condition	Percent (number of respondents)
Yes	31% (16)
No	63% (32)
No response	6% (3)

People told us about different training that they would find helpful:

- Coping strategies
- First Aid
- Safe lifting
- Sign language / Makaton
- Caring for people with drug addiction
- Caring for physical health
- Family workshops

They also told us about the types of information they would find helpful:

- Detailed information on condition
- Information about providing personal care
- Information about self-care
- Information about care equipment

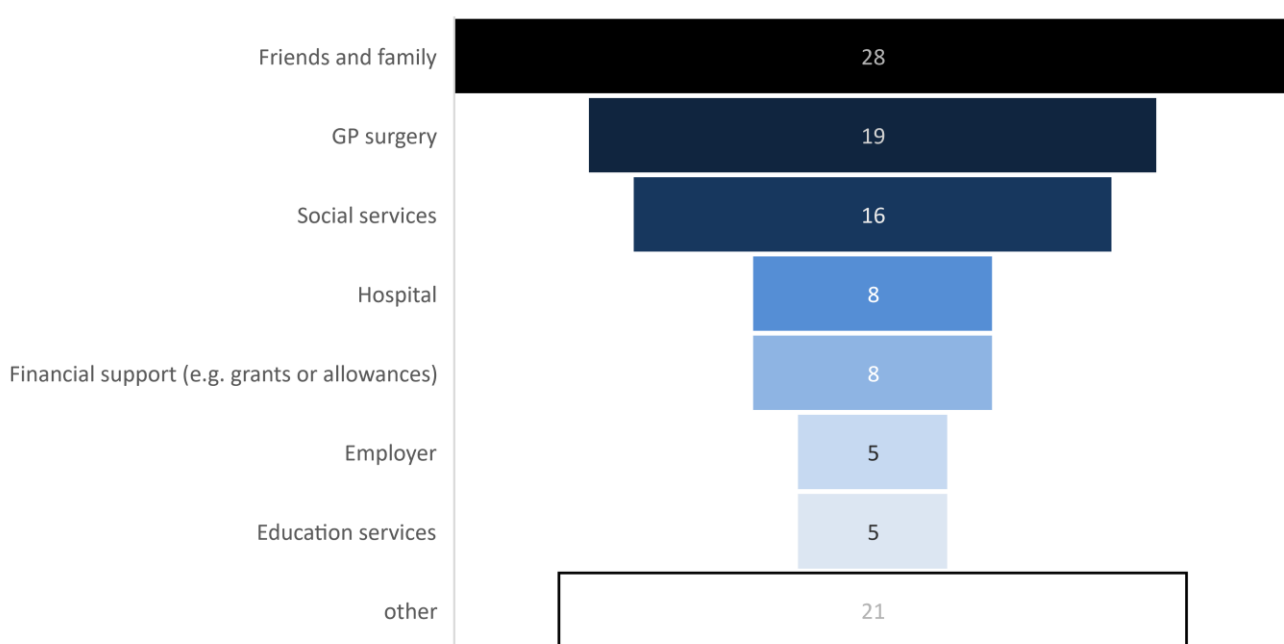
In summary, people told us that they would like more information and training to enable them to better care for themselves and their relatives.

² Improving Access to Psychological Therapies (IAPT) services are a range of psychological therapies for people with common mental health problems and everyday challenges such as anxiety or stress, depression, bereavement or loss, sleep difficulties, anger issues, obsessive compulsive disorder, phobias, eating disorders

Question six: Which of the following do you feel supported by to help you balance your caring responsibilities with work /education and to have a life outside of your caring role?

Most people (28 respondents, 55%) told us that they **feel supported by friends and family** in their caring roles. **Many people also told us that they feel supported by their GP surgery (19 respondents, 37%) and social services (16 respondents, 31%).**

All the participants in one group agreed that their GPs recognised them as carers and gave them extra time (e.g. a double appointment). Another person highlighted that the Learning Disabilities Liaison Nurse at St. George’s Hospital was very helpful and supportive when having to go to the hospital. Feedback on social workers was quite mixed; some were described as good, but a few were not described as positively and where there had been a change in staff carers didn’t have confidence in their knowledge and ability to do things correctly.



Sources of support	Percent (number of respondents)
Friends and family	55% (28)
GP surgery	37% (19)
Social services	31% (16)
Hospital	16% (8)
Financial support (e.g. grants or allowances)	16% (8)
Employer	10% (5)
Education services	10% (5)
Other	41% (21)

People who described other avenues of support mentioned their church, family therapy, Wandsworth Carers’ Centre and services that support the cared for.

Question seven: Are there specific ways of supporting carers to have a life outside of their caring role that you have found helpful, or would find helpful?

Many people told us about various forms of support that help them achieve a balance between their caring responsibility and life outside of their caring role, including:

- Respite
- Home care
- Local church
- Gym/exercise classes
- Singing for the Brain
- Meditation
- Creative writing
- Baked Bean Theatre Company
- Cognitive Behavioural Therapy
- Family therapy
- Family Action
- Mental health services
- Wandsworth Carers' Centre
- Young Carers Wandsworth
- Meeting other carers
- Support groups/Carers' groups
- Day centres
- Financial support
- Housing support

Question eight: Do you generally feel involved in the decisions being made about the care and support of the person you look after?

Most people (34 respondents, 67%) told us that they are involved in decisions about care and support and mentioned involvement via care plans which are kept up-to-date and how they were kept updated with information. However, some people told us that they are “totally excluded” or not involved at all in care and support decisions. This shows a very slight improvement on responses to our 2016 survey when half of the respondents felt valued and involved in the decisions made but 27% felt that they were not.

Involvement in care decisions	Percent (number of respondents)
Yes	67% (34)
No	16% (8)
No response	18% (9)

Question nine: What impact do you think your role as a Carer has on your physical /emotional health?

An overwhelming number of people told us that their caring role has had a negative impact on their physical and mental health. They told us they find caring stressful and challenging, and that providing care often comes at the expense of their own health.

“I neglect myself.”

“I have problems getting enough sleep and have anxiety. I have a bad back from lifting and carrying.”

“Emotionally, I am damaged, always waiting on something to happen.”

“I feel like a computer with a virus and its completely knocked me out. I can’t rest, I am self-harming in regards to not eating properly and smoking too much. I feel isolated and don’t know who I am anymore.”

“I’m suffering from mental and physical exhaustion... my physical health is deteriorating. I’m getting fungal infections etc. constantly because I’m so run down.”

“Stressful, worrying, feel like I’m failing as a parent as I don’t know where to get information.”

“I felt that I had a mental and physical health breakdown which lasted 4 months last winter, when I was caring for my husband and my son.”

“Sometimes I’m depressed.”

“Very draining, my health suffers.”

Two people told us that they found their caring role rewarding despite it being very demanding.

Question ten: What do you think are the main health challenges faced by carers in Wandsworth?

When asked about the main challenges faced by carers, most people identified the following challenges:

- Stress
- Lack of sleep/exhaustion/fatigue
- Self-care (e.g. exercise)
- Depression and loneliness
- Anxiety
- Physical pain (e.g. back pain)
- Lack of support

Many of the responses highlighted the amount of responsibility imposed on carers and that this responsibility is continuous and non-stop (when services are not available it falls to the carer to keep things going):

“Have to do everything yourself. It is me telling the NHS and LEA what equipment my son needs. It is me paying for private therapists out of my son's DLA money to advise on what leg splints (orthotics) he needs.”

“I am taking total responsibility.”

“To always remind him on what to do, taking his drugs, checking the bank account.”

“Being a carer for those with alcohol and drug issues is demanding, [...] random, unpredictable and volatile.”

“The fact the NHS only works 9-5 so there is no help”

Conclusions and Recommendations

From the responses to the survey, we found several themes that need to be looked at further by services to consider how they could better support carers. Some of these themes are listed below.

Easy access to mental health support

Carers particularly felt that they needed to have easy access to mental health coping strategies, wellbeing resources and general support. One carer highlighted that they did have a referral to mental health services but there was a long wait to get the support needed.

Information on available support and what carers are entitled to - everyone's responsibility

Many carers said that they did not know about the various forms of support they could access. More creative ways to reach carers may be needed, and all parts of the health and care system need to be able to quickly identify carers and signpost them to the right information that will get them support as quickly as possible. If a carer is not supported, it will have a wider impact on these services, the health of the cared for and the health of the carer. When a patient has a carer it is important that they are considered and supported as soon as they begin taking on that role, whether this first contact is at a GP surgery, hospital or other service.

More information about the health condition of the cared for

Health, as well as social care services, will come in to contact with carers and recognise them as important in patients care. Our respondents however, felt that it would be really helpful to have more information about the conditions and needs of the person they care for, to help them to support them.

See the results of question 5 for a list of the suggested topics carers would like support with.

Support services for carers that are, or would be, helpful

In question 10 carers told us of the main challenges they face and where services may need to consider supporting carers more:

- Stress
- Lack of sleep/exhaustion/fatigue
- Self-care (e.g. exercise)
- Depression and loneliness
- Anxiety
- Physical pain (e.g. back pain)
- Lack of support

Having heard the life experiences of many carers, it is clear that services need to recognise that most often a carer's role is continuous, that they are supporting people when services are not available or need out of hours support.

Carers told us that the following forms of care are, or would be, useful and could help support them more:

- Respite care
- Home care
- Carers' Events
- Carers' newsletters
- Assistance with application for carer's allowance, financial and housing support
- Family Action Wandsworth
- Mental health support and therapy

- Peer group, support groups and day centres
- Local church
- Exercise
- Meditation
- Massage

Carer's Assessments and finances

Many respondents highlighted that they had not had assessments, however almost all of them spoke about the effects of caring on their physical and mental health as they often provide support throughout the day when services are not available.

There were also a number of comments from those who had received an assessment, suggesting that the assessment process and content may need to be reviewed, including:

- Being told that they were ineligible for services or support, and not being signposted to other information and support
- Staff knowledge about the assessment, entitlements and local services could be improved
- Concerns that assessments are not always carried out by doctors or social workers
- Waiting times for assessments
- Getting more information as a situation changes over time
- Support in claiming entitlements, including financial allowances

It seems particularly important that the carer's assessment includes signposting and easy access routes to support other than that available from the council if thresholds to qualify for financial or council funded services are not met. This could be NHS support, support from other health or voluntary sector providers, and important information to help them in their role and to help them cope.

Carers' situations often vary and change over time; hours spent caring may increase and there may be an incremental impact on their health. It is therefore very important that they have ready access to the information and support that they may need.