



## **“Unsung Heroes”**

### **The experiences of adult unpaid carers in Bexley**

*“We live in a temporary society: interim working is the fashion, as a carer, I am permanent and consistent”*

**October 2018**

#### **Acknowledgments**

Healthwatch Bexley (Healthwatch) would like to thank local carers, carers support groups, charities and other stakeholders for their help and sharing their valuable experiences, promoting and participating in this survey. They include: Albany Park Over 65's Group, Age Uk Bexley, Alzheimers Society Bexley, Bexley Slam, Bexley Library Services, Bexley Snap, Bexley Voice, Carers Support Bexley, Crossroads Care Bexley, Dengate Women's Group (KAB), Evergreen Care, Greenwich and Bexley Community Hospice, Huntingdon's Disease Association, (North Kent), MENCAP (Bexley), MIND Carers Support (Bexley), Parkinson's UK, (Bexley and Dartford Branch) and the Pensioners Forum Group (Bexley).

#### **Executive summary**

This report presents the findings of a broad study into the experiences of 115 Bexley residents, over the age of 18, who undertake a caring role for friends or family. Healthwatch visited many different adult carer's groups to engage with carers and distribute a questionnaire. As a result, those who told us of their experiences were carers for a number of reasons such as mental and physical disability and illness, and throughout different life stages, such as parents caring for an adult child with Autism, parents caring for a disabled child, or an elderly man caring for his wife with Dementia. Visits were made to local charities, community groups and carer support groups and those attending were given the opportunity to complete a questionnaire

about their experiences and views of being a carer. The questionnaire was also promoted on Social Media, ie Facebook, Twitter and Healthwatch Bexley website, all of which provided a link to an online questionnaire.

This report does not explore the views and experiences of Young Carers under the age of 18, as their views were explored separately from this engagement. The Young carers experiences can be found in Healthwatch Bexley report “Young Unsung Heroes” (2018) which can be accessed via the following link:

[http://www.healthwatchbexley.co.uk/sites/default/files/young\\_carers\\_report\\_final.pdf](http://www.healthwatchbexley.co.uk/sites/default/files/young_carers_report_final.pdf)

N.B This report is not an evaluation of the services adult carers use, but of their personal experiences and views of being a carer.

### **Key findings**

- 85% of respondents care for 50+ hours a week or all day and night.
- 29% of respondents care for two or more people.
- 46% have been a carer for 11 years or more.
- 81% expect to be a carer until they or the person they care for dies or goes into a home.
- The majority of respondents said caring affected or sometimes affected their physical and emotion health and wellbeing, social life, finances, ability to work, relationships and friendships.
- 49% of respondents consider themselves to have a disability or long term health condition or illness.
- 70% know where to get help and support.
- 61% do not feel supported to plan for the future and only 25% have a plan in place for an emergency.
- 95% worry or sometimes worry about the future
- 24% of respondents have had a carer’s assessment.

### **Key recommendations**

1. The Local Authority, CCG, health and social care professionals, and community sector need to continue to work together to identify hidden carers, especially young carers and the elderly, so that they can be signposted to and access support available, to help carers continue in their caring role.
2. This report found a lack of knowledge and confusion around Carer’s Assessments. The Carer’s Assessment should be actively promoted, which

would increase understanding and encourage carers to ask for an assessment if they want or need one, including those who may not have considered themselves to be a carer.

3. Carers in Bexley should be encouraged and helped by the local authority, community sector and professionals such as GPs, to put detailed plans in place for an emergency/crisis, to prevent them asking for help at crisis point and help alleviate the worry of what will happen in an emergency. Details of examples of schemes used by Barking and Dagenham and Derbyshire can be found via the following links:

<https://www.bournemouth.gov.uk/AdultSocialCare/Carers/CarersInCrisisEmergencyBackUpScheme.aspx> <https://derbyshirecarers.co.uk/emergency-planning-derby-city>

4. For some carers the option of counselling may help them come to terms with some of their emotions, by providing a safe place where emotions can be explored in a non-judgmental way and support them in difficult situations. A review of counselling services for local carers should be undertaken.

## **1. Introduction**

A carer is a person who provides support, care and help to family member or friend who would be unable to manage without their help. Care is provided for many reasons such as age, physical or mental illness, addiction, or disability and anyone can become a carer at any age and any time in their life (Carers Trust, 2018). Carers may provide help with household tasks, personal care, finances, travel, medication, appointments, or provide emotional support and companionship to the person they care for without payment. An unpaid carer is different to a care assistant or care worker, who may perform similar tasks or duties but are employed to provide care and help (Carers Support, 2018).

According to Carers UK, (2018) carers are often forgotten or taken for granted yet relatives, friends and family provide care estimated to be worth £132 billion, more than the NHS's annual budget in England of £124.7 billion (Kings Fund, 2018). The social care sector and NHS rely on carers, yet Carers UK suggest that carers often feel undervalued or unsupported (Carers UK, 2018). The report "State of Caring 2018" (Carers UK, 2018) found that being a carer can impact on the carers own physical and mental health, finances and ability to work, as 72% of carers had suffered mental health issues as a result of caring and 61% said that caring had affected their physical health, whilst 35% reported having to give up paid employment as they were unable to juggle work responsibilities with a caring role.

According to the Carers Trust there are seven million carers in the UK, which is expected to rise by 3.4 million by 2030 (Carers Trust, 2018). Locally the 2011 Census found that there are 23,522 unpaid carers in Bexley, which equates to 1 in 10 or 10.2% of the Bexley population. However, with Bexley's changing demographics such as its ageing population and an increase in single parent households, this number is predicted to rise (JSNA, 2014). The Care Act 2014, states that in England all councils should provide an assessment of the support needs of any adult with caring responsibilities (Care Act, 2014). The true number of carers in the UK and Bexley may not be known as many carers do not consider themselves to be a carer, as they are looking after a family member and feel it is their duty. As a result they may not be assessed, access the help, support or financial benefits they may need or be entitled to (Carers Trust, 2018).

This report was undertaken as the Healthwatch Bexley report the "Emotional Wellbeing of Young People" found that 20% of the young people self-reported as being a Young Carer (Healthwatch Bexley, 2017). With the number of carers predicted to rise (Carers Trust, 2018), the purpose of this report is to explore the views and experiences of unpaid carers in Bexley Borough.

## **2. Methodology**

A questionnaire was compiled with the help of the MENCAP carers support group, who offered advice on what should be included in the questionnaire based on their experiences as carers.

Healthwatch Bexley then visited many local events, libraries and carer support groups such as Age UK, the Alzheimers Society and Mind Carer support groups in spring 2018, to engage with carers. We explained what Healthwatch Bexley does and that part of our role is to help residents have their voices heard. Attendees were subsequently invited to complete a hard copy of the questionnaire or complete the questionnaire online. Representatives from MIND in Bexley, also took hardcopies of the questionnaire to groups we were unable to attend and returned any completed questionnaires to us, whilst other charities and organisations promoted the online questionnaire amongst their members. The online questionnaire was also promoted via the Healthwatch Bexley website and Social Media which provided a link to the questionnaire. The questionnaire was completed by 115 unpaid adult carers living in Bexley Borough, although not all carers completed all the questions, which accounts for the differing response rates (n).

Quantitative and qualitative data was collected to fully explore carers lived experiences and capture their views, with carers being asked to comment and expand on some of the answers given to provide a deeper insight into their experiences.

**Questions and topics included:**

- Details of the caring role.
- Carers own health and wellbeing.
- Accessing information and support.
- Carer's Assessment
- Future planning
- Challenges of being a carer.
- The best thing about being a carer.
- Demographics

**Limitations**

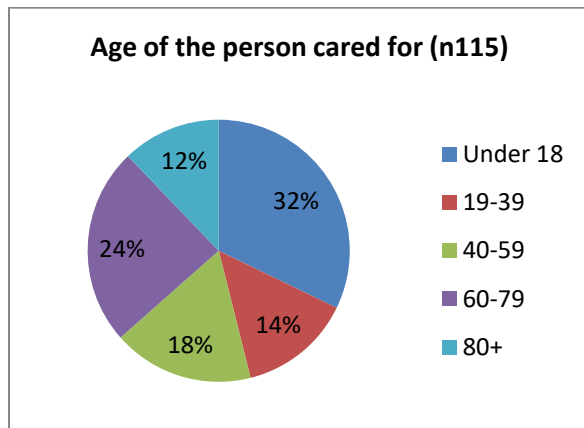
Healthwatch Bexley acknowledge that this may not be a representative sample of carers living in Bexley, as only 115 carers, a relatively small number of the known number of carers in Bexley Borough shared their views with us. The study is based on the self-reported views and experiences of local carers who have a caring responsibility for a wide range of reasons ie addiction, dementia, learning disability, physical and mental ill health, sensory impairment etc. Carers are caring at different stages and ages in their own lives and the carees life ie husbands caring for a wife, adults caring for elderly parents or parents caring for children with additional needs. Some carers had retired, whilst others were trying to juggle caring with work or looking after other family members such as young children. Therefore, the results of this study may not be generalized to all carers in Bexley as needs and circumstances will vary depending on who is being cared for and by whom. The results of this study do however provide a starting point for discussion and further exploration as many of the findings are common amongst all the different groups of carers, for example the need to plan for future or having a carer's assessment.

This report may be distributed to carer support groups, charities, Bexley Local Authority, Health and Wellbeing Board, Overview and Scrutiny Committee, Bexley Clinical Commissioning Group and other stakeholders.

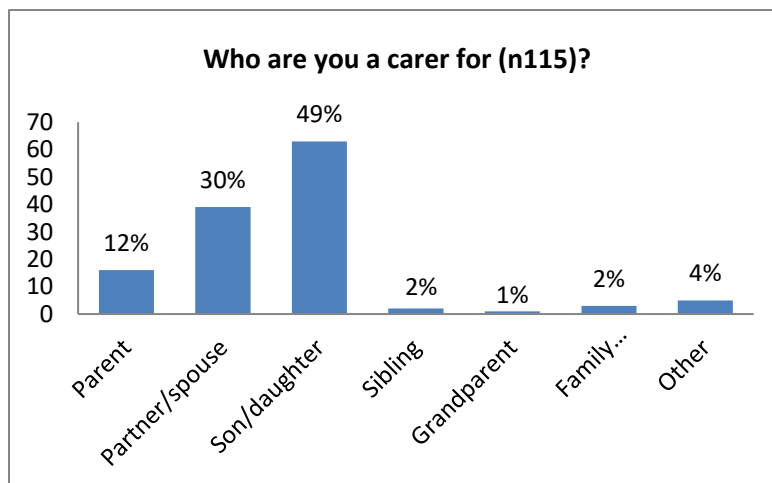
### 3. Results

#### The Caring Role

The questionnaire asked respondents about the nature of their caring role, how many people they care for, the age of the cared for person, and if they share their caring responsibility with someone.



Almost half of the respondents stated they provide care for their son or daughter (49%), followed by partner or spouse (30%) and a parent (12%).

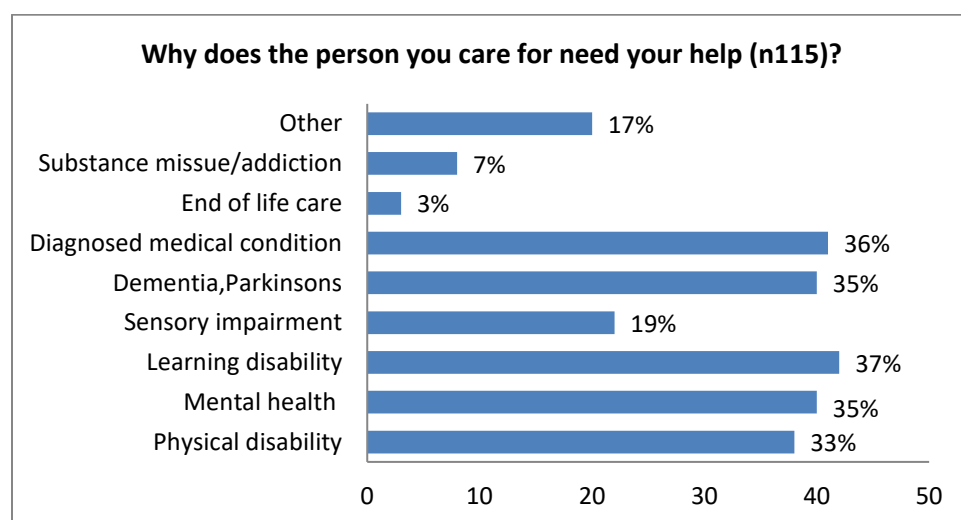


The majority of respondents stated they care for one person (71%) with one in five (21%) caring for two people, and 8% caring for more than two people.

Just over half, 52%, did not share their caring responsibilities with anyone else, and 48 % reported that they shared their caring role with others.

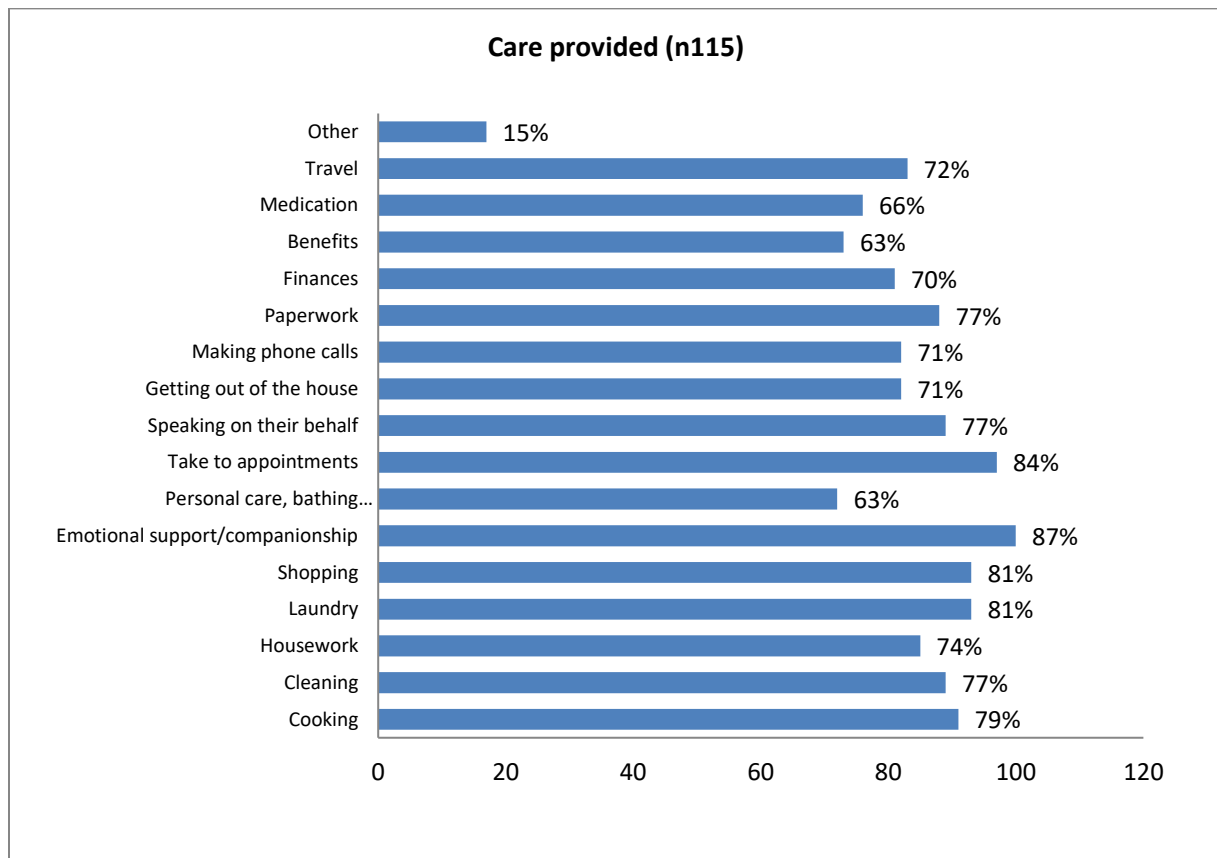
The majority of those who were able to share their caring role, 59% shared caring responsibilities with their partners, 18% shared with their son or daughter, 12% with their parents, 18% with siblings and 12% reported that they had help from paid carers.

The reasons for needing care is displayed in the graph, with a learning disability being the most commonly cited reason, followed by a medical condition, mental health issue and dementia and a physical disability.



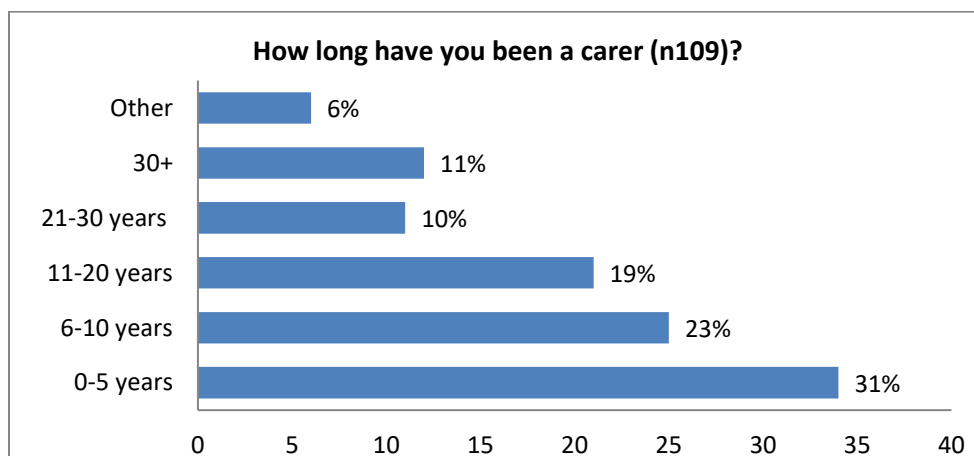
Carers typically take on a number of duties on behalf of the cared for person, which in combination contribute to a significant amount of time. The type of care provided by respondents is displayed in the graph and the percentages demonstrate that the many of the respondents undertake the majority of tasks, with emotional support and companionship attracting the highest percentages, followed by accompanying to appointments as well as undertaking day-to-day tasks such as laundry, shopping, cooking and cleaning.

## What care do you provide (n115)?



The majority of respondents (77%) live with the person they care for, with 7% stating they sometimes live with the person they care for and 18% did not live with the person they care for.

Nearly half of the respondents (46%) have been a carer for 11 years or longer, 11% reported being a carer for 30 years or more.



We asked how long people expect to be a carer and 81% of respondents told us that they will be a carer until they or the cared for person dies or goes into care, with 10% citing they would be a carer *“As long as I am able”*.

Some of the comments recorded when answering the question included:

*“Not as long as I have been.”*

*“18 years as a mum.”*

*“I never expected or wanted to be a carer.”*

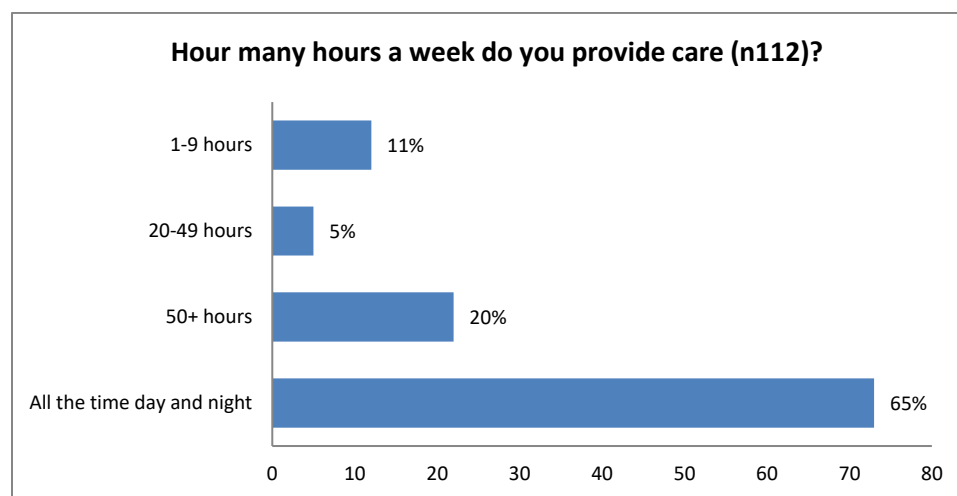
*“It wasn’t part of my life plan.”*

*“All the time I’m alive.”*

*“Until my mother can no longer live alone.”*

*“As long as it takes and I am able”*

The majority of respondents (85%) provide care for 50+ hours a week or all the time night and day. This is noteworthy, as people who provide care for 50+ hours per week are twice as likely to report ill health compared to those who do not provide care (Carers Trust, 2018).



The majority of respondents (79) were drivers and 78% owned their own car and 52% stated they use public transport. The comments recorded for transport included:

*“I think we should get a Freedom Pass for a carer to travel....he*

*has a Freedom Pass but is unable to travel independently so I have to accompany him and pay.”*

*“My son relies on me to get him to college and appointments.”*

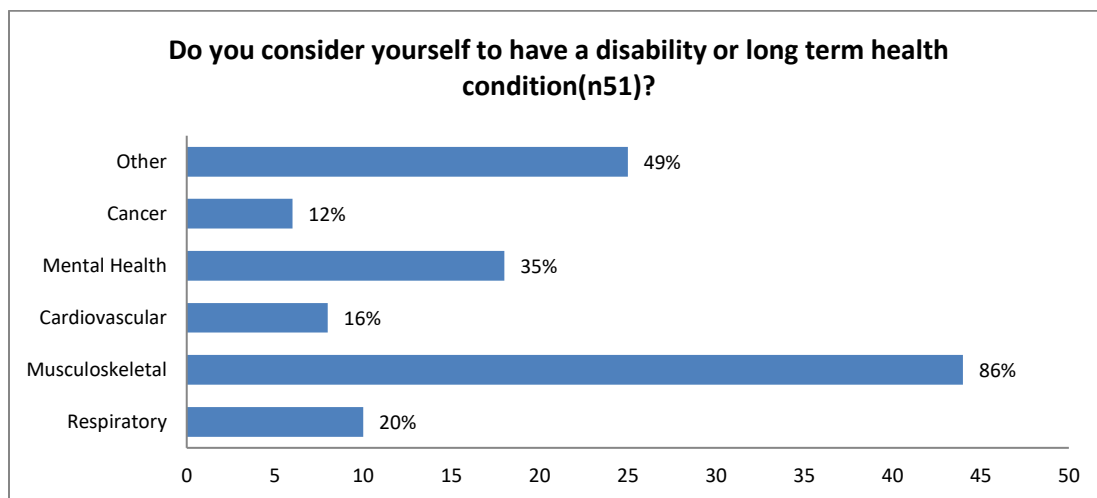
*“Couldn’t get help with transport at all.”*

*“Mum has a Blue badge.”*

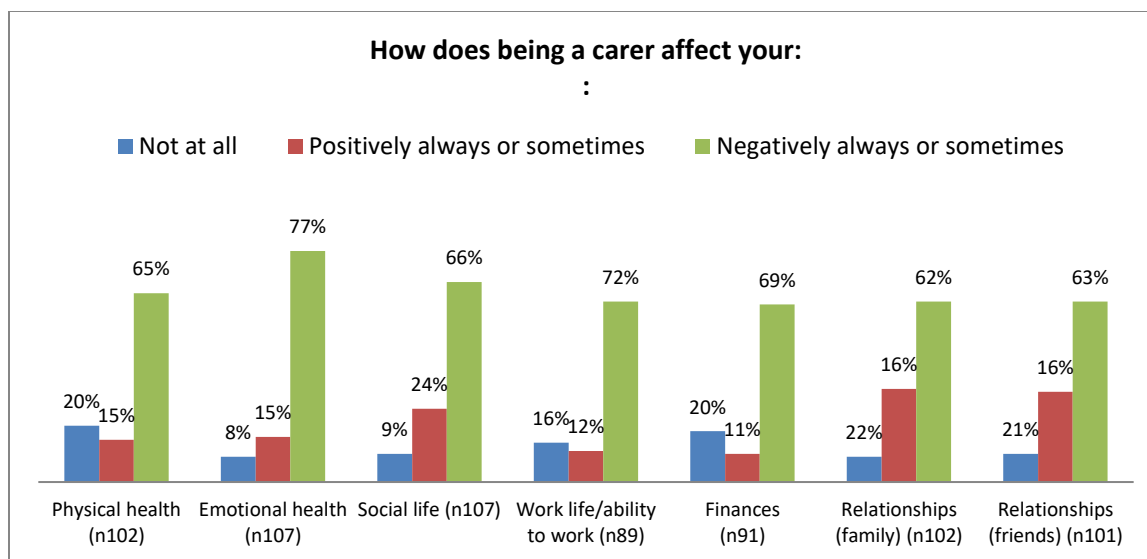
## Carers own health and wellbeing

Being a carer may have a significant impact on a person’s physical and mental health, with many carers living with their own long-term health condition or disability whilst providing care.

Nearly half of the respondents (49%) consider themselves to have a long-term disability, or health condition, with 86% reporting having musculoskeletal problems such as back pain, sciatica or knee problems. More than one third, 35%, reported having poor emotional health, depression, anxiety, low mood, sleep deprivation or feeling tired and worn out.



The questionnaire asked respondents to reflect on how being a carer affects their physical and emotional health, social and working life. The majority of respondents stated being a carer “always or sometimes” negatively affected all aspects of their health, with emotional health attracting the most negative answers.



This question attracted a significant amount of additional comments, illustrated in the box:

*"My mother does not sleep well so we get lots of calls throughout the night ...then have to work the next day."*

*"It is impossible for me to work which hurts financially but also makes friendship groups much smaller."*

*"It's my whole life, it gets too much but I have no alternative."*

*"It has made me more assertive by having to be an advocate."*

*"I love those I care for and am duty bound to do it, but there's no upside to caring. Got exhausted last year and tried to kill myself. It wasn't a cry for help."*

*"My caring role is draining at times, especially when my son's education is not going well. My day is frequently interrupted by phone calls and emails about incidents and situations arising at school and I often have to collect my son in the middle of the day."*

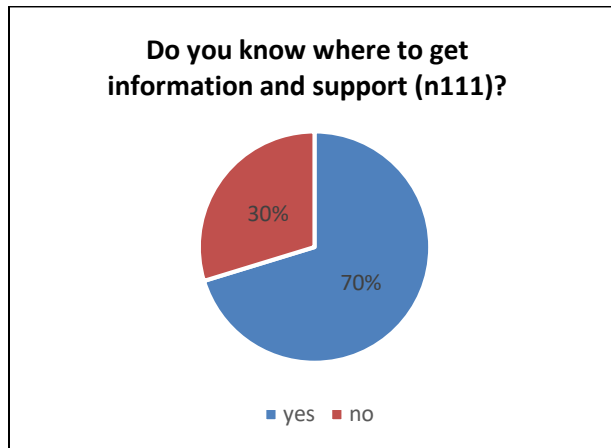
*"Your life is never your own."*

*"My wife is dominant/demanding and Parkinson's damages her memory so it makes life difficult."*

*"I sometimes feel I haven't got a life of my own but I am trying to turn that around."*

## Accessing Information and Support

Accessing information and support is vital for carers to be supported in their role and the majority of respondents (70%) said they know where they can access information and support. However, one third of respondents said they did not know how to find information, which for some had a detrimental impact on their emotional wellbeing as a carer due to isolation and loneliness.



*“Information is irrelevant when there’s nothing at the end of it.”*

*“I’ve had no information regarding support. I have no idea where to get any or where to look.”*

*“I am grateful for the support I get but often realise there are other things out there for me that I don’t know about.”*

*“I have had no support until 2016. I was not aware of Mind Carers Support or anything else. I cared for my mum and brother on my own for over 10 years because I have two kids and the caring role was intensive and I had health issues I could not explore options. So I was alone. There was no help offered by my own GP or my brother’s team until 2016 after numerous complaints. I think it should be compulsory for GP’s health professionals to seek out and guide carers towards help and support because we are too busy, tired, ill frustrated and don’t have the opportunity.”*

*“Information is difficult to source.”*

*“It’s not the knowing about it, it’s the getting access to it.”*

The majority of respondent's told us that they find information about support for carers, from other carers, charities and the voluntary sector, such as MIND carers support, Bexley Voice, Carers Support, MENCAP, Age Uk, and the Alzheimers Society.

Just over one third, 32%, said they get information from professionals such as GPs and 21% from social workers. Others ways of finding information included leaflets and searching the internet.

*"Most of what I've learnt is through other carers."*

*"A very good source of information is Mind Carers Support Group."*

*"Alzheimer's Society very helpful and supportive."*

*"Bexley Voice is where I get most of my support and advice."*

*"Carers Support are a lifeline."*

*"Bexley Mencap and other carers."*

*"Would contact Age UK."*

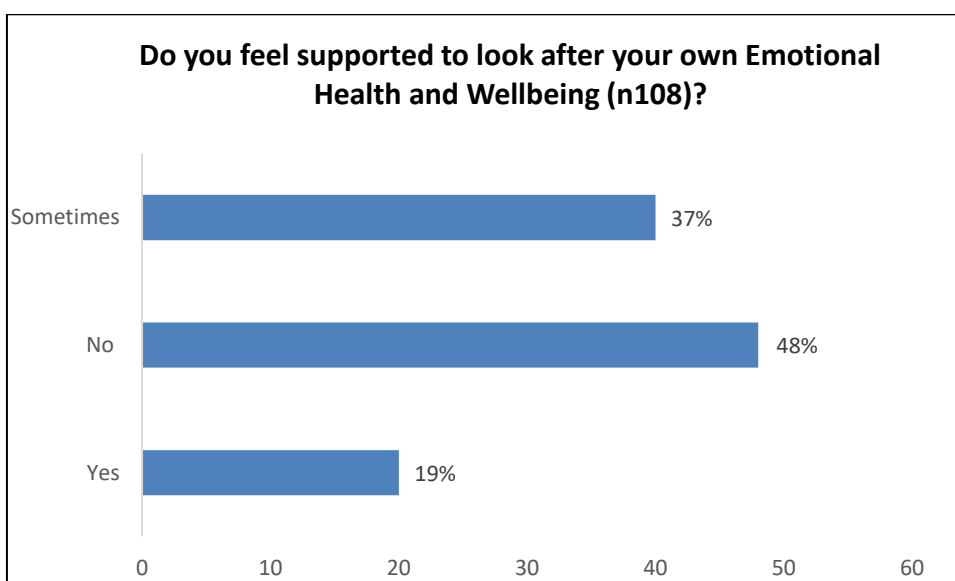
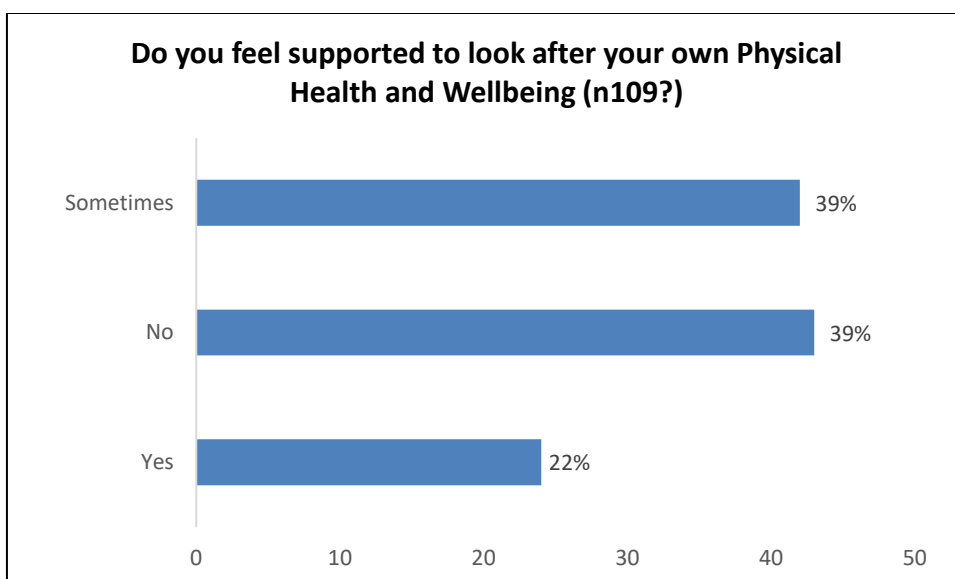
*"Nurse and healthcare assistants are very good."*

*"Internet, I search as and when I need help."*

### **Carers health and wellbeing**

As highlighted, carers frequently undertake their caring role whilst managing their own long term health condition. Making sure that carers are supported in looking after their own health is therefore fundamental to ensure their health is not compromised or deteriorating due to their caring responsibility. Cancelling doctor's appointments is commonplace amongst carers as they are unable to leave the cared for person.

Just over one in five (22%) of respondents said they felt supported to look after their own physical health and wellbeing, which decreased to 19% for looking after their own emotional health and wellbeing. Almost half of the respondents (48%) said they do not feel supported to look after their emotional health and wellbeing, with 37% stating they sometimes feel supported. Similarly for physical health, 39% said they do not feel supported to look after their physical health with 39% stating they sometimes feel supported.



*“My husband and I ensure we both take regular breaks separately from our caring roles.”*

*“Since I was introduced to Mind carers support I am getting emotional support and help and advice. Until I met Andy and Imogen I was completely alone. I now no longer feel alone and am now starting to take care of myself and my family also as well as care for my mum and brother.”*

*“Get emotional support from family but not practical.”*

*“At the moment taking a break from my caring role seems an impossibility*

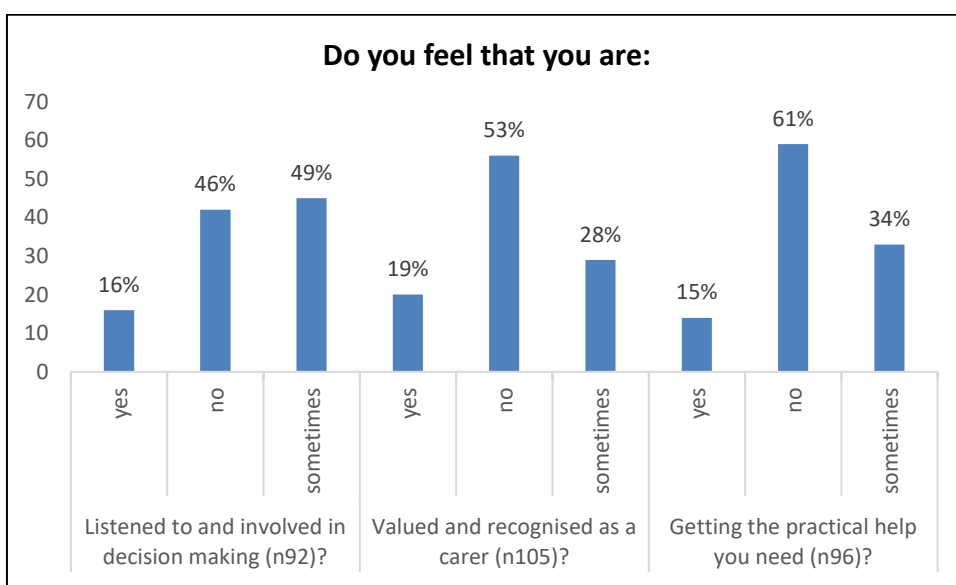
*as the person I care for (my wife) is very clingy and refused to stay at home for any amount of time to allow me a break.”*

*“I have had a severe back and sciatica problem since May 2017, and despite telling Bexley MSK that I was a carer for my husband who had a stroke recently and dementia. It did not make any difference and I have waited until mid-December (after I rang PALS) for an MRI.....It’s not an effective use of resources and it leaves patients in pain for months”*

*“Carers should get three monthly health checkups, as we are more likely to avoid going to the doctors because we are busy, and more likely to suffer mentally because of our caring role.”*

Carers play a vital role in supporting people with long term health conditions to live independently, which subsequently reduce the need for health and social care. We asked participants to comment on to what extent they feel listened too and involved in decision-making and if they feel valued and respected as a carer in addition to receiving any practical support they may need.

The survey demonstrates that some carers, particularly those who have been caring for many years, feel more listened to and recognized as a carer than 10 years ago, which is a positive finding. However, the majority said that more should be done to facilitate carers to be involved in decision-making and making sure carers are able to access practical support.



**Do you feel listened to and involved in decision making?**

*"Bexley have made progress in the way carer's views are now listened to, they still have a long way to go."*

*"I feel as a carer I am more likely to be listened to now than 10 years ago, but hope we can be included and listened to more when the council are considering and making changes."*

*"I feel completely ignored and that no one cares."*

*"Where would I go to get listened to? How would I get away to get there?"*

*"I feel at times they seem to pay too much attention to the person you are caring for and forget the carer, especially married couples."*

**Do you feel valued and recognised as a carer?**

*"I am recognised as a carer but don't feel valued, except by one social worker we had."*

*"I would like to be respected, valued and supported not taken for granted by services."*

**Do you feel you are getting the practical help you need?**

*"I receive most of my practical support from my son's day center and from Bexley Mencap. Help with direct payments, which at the beginning was a minefield to understand. Needed and got help with this from Bexley Mencap."*

*"Carer's support provided help for benefits claim. Without this help would not have been successful."*

*"Everything revolves around money and there is none."*

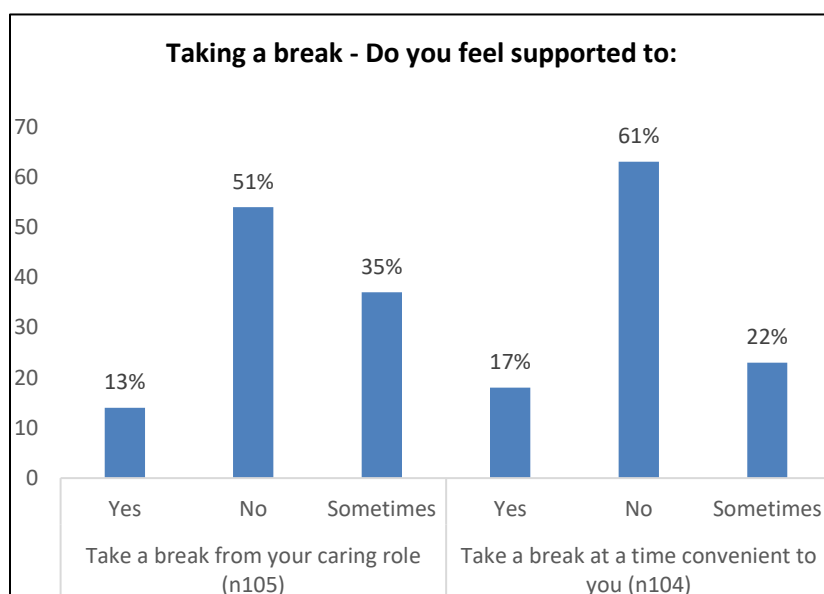
*"I have no support at all as a carer and a single parent."*

## Break from the caring role

Supporting carers to have a break from their caring role is identified as crucial to ensure carers emotional and physical health needs can be met.

Half of the respondents (51%) felt that they were not supported to take a break from their caring role, and 35% felt they were sometimes able to take a break, whilst 13% felt supported to take a break from caring. Taking a break included support from other family members or friends or respite care.

Moreover, 61% stated that they were not supported to take a break from caring at a time convenient to themselves, with 22% stating they were sometimes supported to take a break from caring at a time convenient to themselves. Less than one in five, 17%, felt they were supported to take a break at a convenient time.



*“Respite always comes with restrictions, 4 weeks-28 days of the year which is not enough.”*

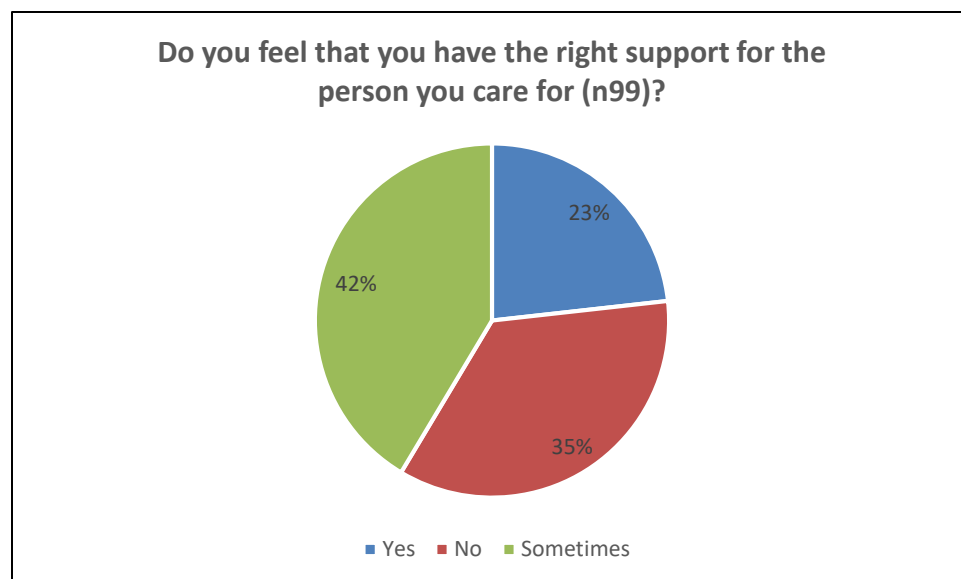
*“Where is the support supposed to come from, even when I’m fed up I’ve got to carry on.”*

*“Respite care for someone younger is non-existent.”*

The respondents were asked if they felt the cared for person has the right support in place. Less than half, 42%, stated that they sometimes had the right support in place

whilst nearly one quarter, 23%, felt they had the right support for the person that cared for. However, more than one third of respondents, 35%, stated that they felt they did not have the right support in place for the person they looked after.

Some respondents said the changing needs of the cared for person was not always recognized, which means that support requirements may vary.



*“Currently we receive the right amount of support. However, due to my husband’s Alzheimers as his health needs change we will need to use the services. Hopefully they will still be there for us to use.”*

*“Very pleased with caring support team for my father.”*

*“Not yet but we are working on that and things are starting to improve in terms of awareness and involvement.”*

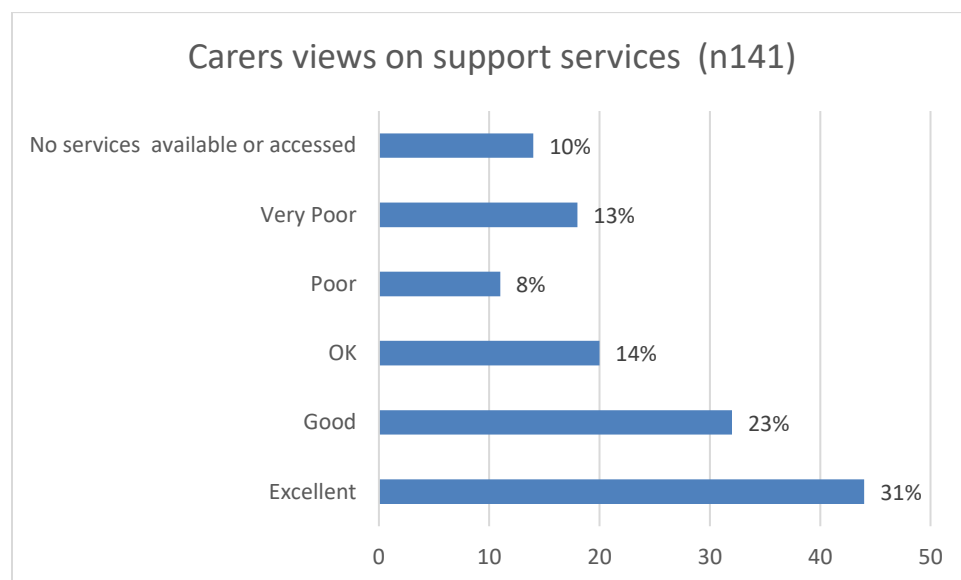
*“No family, no emergency support, LA making stress and life difficult and this has had a very adverse unexpected effect on my health.”*

*“We manage, but I know there are other means of support that he could benefit from but apparently we are not considered needy enough.”*

## Support Services.

Carers were asked to rate the support services that they access on a scale 1-5, with 1 being Excellent, 2 Good, 3 Ok, 4 Poor and 5 Very Poor. Carers were able to respond for each service they had used, which resulted in multiple responses from some

carers. The graph below shows that 31% of carers rated support services as Excellent and 23% as Good. However; 10% of carers (n14) said that they either did not access support services or that support services were not available to them, whilst 13% told us support services were Very Poor.

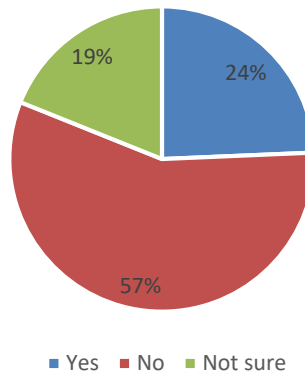


### Carer's Assessment

Carers are entitled to a carer's assessment as part of the Care Act 2014. The carer's assessment should identify how the carers are coping with their caring role, how it affects a person's physical and mental health needs, leisure time and relationships. The carers assessment is a key opportunity to provide information about services and benefits, as well as signposting to local organisations, who can support carers. Not all carers may want or need an assessment but they should be aware that they can have an assessment if they wish.

The survey demonstrates that less than a quarter of respondents (24%) stated they had had a carer's assessment, with 19% not sure if they had had one. However, the majority of respondents (57%) stated that they had not had or were unaware of ever having a carer's assessment.

**Have you had a carer's assessment (n111)?**



*"I took on the role due to circumstances, so I have not had and am not aware of an assessment."*

*"Have spoken to primary care workers (so not sure if I have been assessed during this period)."*

*"I don't remember having one at all."*

**If you have had a carer's assessment when was it (n12)?**

6 carers told us they had had a Carer's assessment between January 2017 and January 2018, of the remaining 6, 2 had been assessed between January 2015 and January 2016, the remaining 4 had been assessed prior to January 2015, with 1 stating that their last assessment was in January 2010.

We asked respondents what had changed as a result of the carer's assessment, with some stating that direct payments had made a positive difference coupled with practical amendments for the cared for person. However, many felt that the carers assessment did not directly impact on their own needs:

*"Direct payments have made a huge difference."*

*"Only good thing that came from it was Mind Carers Group."*

*"Direct payments. These are used for a variety of activities for my child."*

*"There was an assessment which resulted in a bannister being fitted ....it's helpful, but in terms of MY needs, it's insulting and pitiful. Carers are invisible. I don't get minimum wage for the 24/7 care that I provide."*

*"I was sent a list of places to possibly go to or ring for group meetings but they were not always possible to attend. So a lot was unhelpful, as just supplying telephone numbers is not enough."*

*"I contacted a Parkinsons nurse at Xmas as I was not coping and she got an extra tea time call for me."*

*"No change. Disgusted at the constant change in social workers and having to start again, time and time again."*

*"My mum had a carers assessment. But I see no action or changes as a result. They did not even get back to us. Nothing was done. It was a total waste of money."*

### **Planning for the future and emergency care**

The changing nature of chronic illness and the uncertainty that surrounds it makes planning for the future a difficult task. Planning for the future also includes emergency care if the carer becomes unwell. We asked respondents to what extent they felt supported to plan for the future of which the majority, 61%, stated that they did not feel supported to plan for the future, with 26% stating they sometimes felt supported.

When asked who takes over the caring role if they become unwell, the majority of respondents (55%) reported that other family members would have to step in to undertake the caring role. However, more than one third, 36%, stated there was no one who could take over the caring role, with 4% said becoming ill was not an option.

*"If it comes to it my husband can make the effort to look after himself with reminders from me."*

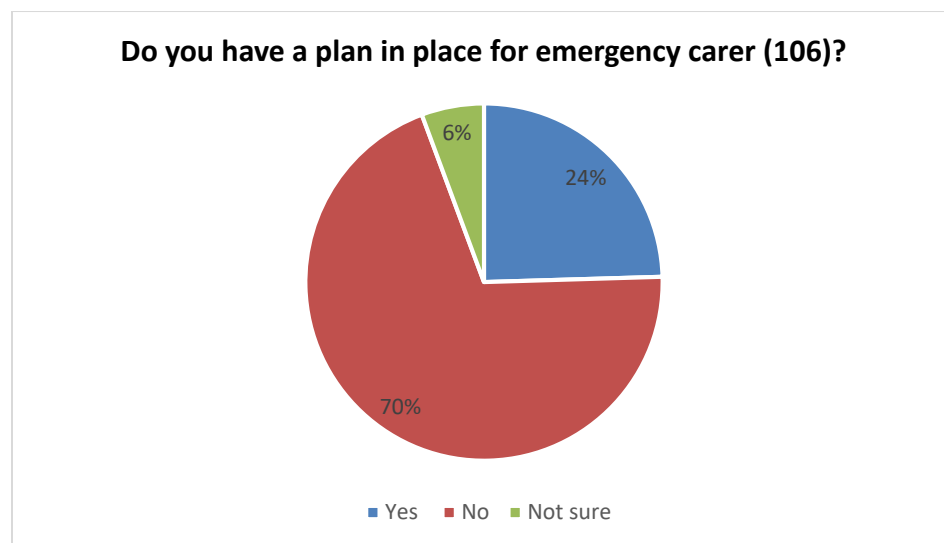
*"No one, illness is not an option."*

*"No one, we just try to muddle through."*

*"I can't be unwell."*

*"My husband or daughter but not to the same level and not easily."*

Worryingly, the majority of respondents (70%) do not have any care plans in place in the event of an emergency, whilst 6% were unsure if they had plans in place and 24% reported that they had an emergency care plan in place. The majority stated that family or friends should provide care in case of an emergency, whilst some felt that support services should step in.



*“Luckily we have never had to use it so we don’t know how good it would be for an emergency or how effective or easy it would be to access.”*

*“The only emergency care we have ever had was when she was ill and fell and stayed in A and E.”*

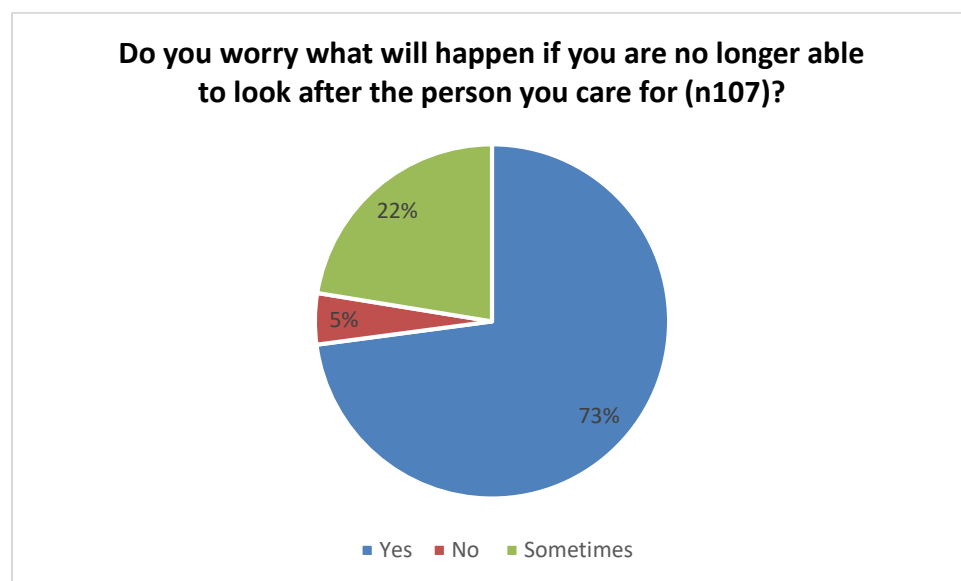
*“Family are around so would jump in to cover.”*

*“I would have to call social services for help.”*

The type of support identified as significant in an emergency is information and a point of contact. Information relates to what support may be available and who to contact, particularly if family or friends are not an option.

We also asked respondents if they worry about what might happen if they are no longer able to look after the person they care for. The majority of respondents (73%) stated they worry what may happen if they were no longer able to care for the person they care for, whilst 22% said they sometimes worry and 5 % do not worry (see graph). The anxiety around this may also be due to respondents not being confident that the

right support would be provided, with the majority stating they were not confident about this.



The comments recorded for this question demonstrate the significant emotional distress families can experience when thinking about the future and how the cared for person may be looked after:

*“My son is fairly young and I am in good health so currently this is not a concern but going forward it is likely to be”.*

*“My daughter has offered to have my son live with her but she lives in Buckinghamshire, so it would be a total life change for both my son and daughter and her family. Her life would never be the same and the same restrictions that I face on a daily basis would impact on her life. I don’t really want to put this responsibility on her”.*

*“Caring can be tough and isolating. Everyone needs a life, but it is asking for help without being judged. My concerns are that support would be put in place who do not know my son. The council are forever changing their minds about services, people come and go- we live in a temporary society. Interim working is the fashion, as a carer, I am permanent and consistent”*

*“Both my husband and I are old (81/82) and we want everything in place for her so she will have continuity of treatment as we will not be there to ensure this happens.”*

*“It happened to me once....my son decided to be in a shared living scheme when I was unwell. He has stayed in that scheme even though I am not ill now.”*

*“Do not believe he will get the practical and emotional help he needs. He says he will kill himself when I go.”*

*“Need to take professional guidance on how best to provide financially, socially and living situation”*

*“We worry all the time and are both on medication to help with sleeping due to stress and anxiety.”*

### **The challenges of being a carer**

The respondents were asked to reflect and comment on what their biggest challenges of being a carer are. Many of the comments recorded related to having to “constantly fight” for services and support coupled with “not being listened to” and a “lack of understanding and empathy for our roles”. Additional challenges were related to financial hardship and the struggle to maintain employment.

Many carers spoke of the emotional and physical strain of being a carer, including feeling lonely and isolated and accepting being a carer. Again, the uncertainty around the not being able to plan for the future attracted a lot of comments:

*“Not knowing what will happen to him in the future. We lack confidence in providers. I have concerns for the future about suitable places to live, with the right support network making decisions about medical treatment or where to live on behalf of someone else, who may not be able to communicate their own wishes sufficiently.”*

*“Emotional side is draining and tiring”*

*“Not being able to plan ahead and knowing how my son is going to cope at various stages of his life.”*

*“Not knowing what will happen in the future.”*

### **How the caring role may be supported**

The questionnaire asked respondents to comment on what may help them most as a carer. Additional support and continuity of care was highlighted, such as support

groups in the evening or weekend, for those who work, coupled with having a key worker who can support the family and build relationships.

### ***Support and services***

*“More community support for vulnerable people with complex needs”*

*“Having a key worker to support me and ensure I have what is needed”*

Carers also highlighted information and advice on what support and services that are available as significant to their caring role:

### **Information and Advice**

*“Easier access to services and knowledge about services.”*

*“A comprehensive guide on what’s available and how to access support.”*

*“It would be useful to know what’s available so I am prepared for any eventuality in the future.”*

Being listened to was also identified as important in addition to a greater appreciation of the caring role amongst professionals:

*“To be heard and listened to by doctors and the teams of carers, nurses.”*

*“For my own health team to appreciate my challenges and the effect of my caring role on my health and time ...”*

Many respondents also spoke of the lack of respite available to them and stated that being able to take a break from their caring role would help them:

### **Respite**

*“I would love to go away for a few days or a break knowing I had nothing to worry about while I was away.”*

*“Being able to take him somewhere and leave him in safe hands without me”*

Lastly, being able to maintain employment or indeed, access financial support to be able to give up work was suggested by some carers:

#### **Financial and benefits**

*“More financial assistance or respite.”*

*“I would like to be able to give up work.”*

*“Need to get back to work earning some money.”*

#### **The best thing about being a carer**

Despite the many significant hardships of being a carer, there are often positive consequences on the individual from performing this role, as carers go through a process of reflection, take on additional responsibilities and gain new experiences.

For carers who access support groups, peer support is identified as a key benefit as new friendships are formed with people who share common ground. The caring role also had a positive impact on confidence and self-worth, as carers felt they were making a difference. The love and respect for the cared for person is clearly demonstrated in some of the comments:

*“Bexley Voice is a fantastic parent support organization whose expertise, knowledge and support is invaluable.”*

*“Friendship and support from parents in a similar position.”*

*“It gives me a sense of increased self-worth”*

*“I feel I am making a difference. Having a sense of community spirit in carers meetings, having respect for each other. Feeling proud and overwhelmed that as a carer I have remained consistent throughout my son’s life and aimed to keep continuity for him. I have dedicated my life in caring for 35 years to my son with a learning disability, this lifelong caring role is very different to other groups of carers eg caring for the elderly”*

*“Joined social groups who encourage friendship, activities, socializing for wellbeing. As a carer it’s easy to become isolated and fearful. On the upside I enjoy helping those I care for maintain dignity and enjoy their lives as best they can”*

*“Love Bexley voice we are a family”*

*“The best thing about being a carer is being able to look after a child who has special needs and see them strive and grow in all that he does.”*

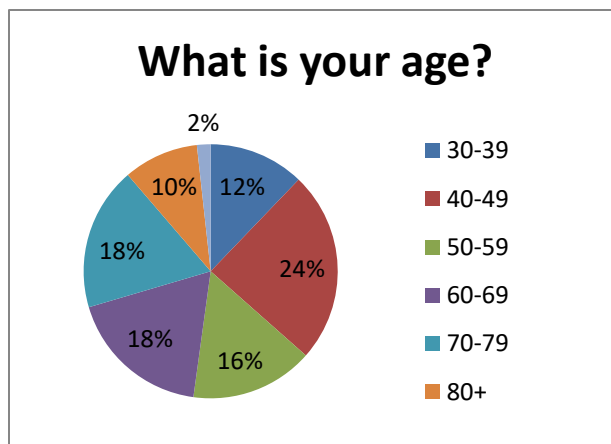
*“A chance to payback my wife for all she has done for me in the past”*

*“Giving back to my parents after all the help they have given me.”*

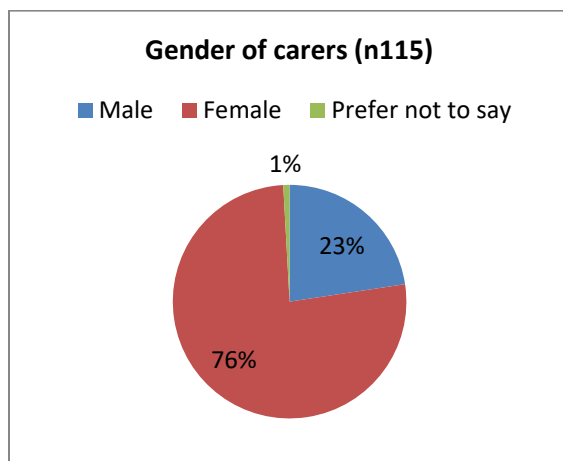
*“Hoping it makes my wife’s life better”*

## Demographics

No respondents were under the age of 30, 28% were aged 70 or over, 34% were between 50-69 years of age, and 36% were between 30-49 years of age.

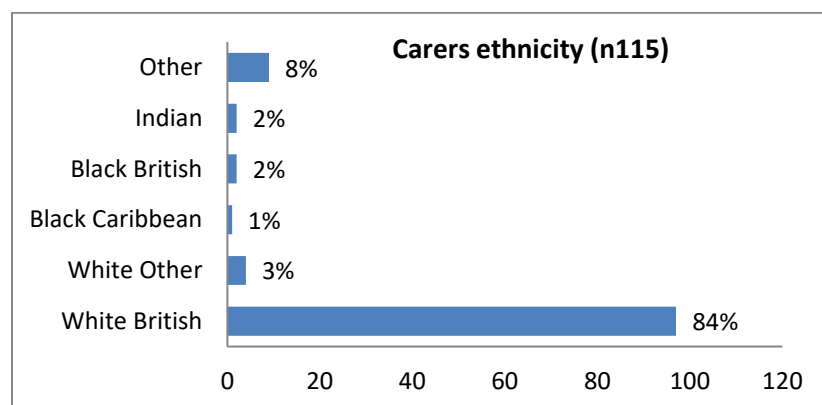


76% of respondents were female and 23% male



## Carers ethnicity (n115)

The majority of respondents were white British (84%).



## Discussion and Conclusion

It is evident from this survey that carers take on significant responsibilities as part of their caring role, with the majority providing care for 50+ hours per week. This is likely to have a significant impact on carers physical and mental health, social wellbeing and the ability to maintain employment.

In contrast to recent research by Carers UK (2018) only one quarter of carers in this survey have had a carer's assessment, with some of these dating back over five years. Identifying carers and ensuring they are aware of their right to a carer's assessment is crucial to support carers in their caring role, as the carers assessment provides a unique opportunity to find out information and advice about support coupled with signposting to local services. The carer's assessment is also a key opportunity to ensure carers have an emergency plan in place in the event of an emergency.

Moreover, additional efforts should be placed on identifying carers needs as almost half consider themselves to have a long term health condition or disability, which is likely to impact on their caring role. It is also important that carers do not always identify themselves as a carer, as they are caring for a child or a loved one. Increased understanding of the caring role from professionals about how people experience their caring role is therefore important to address any emotional support that may be required.

Carers play a key part in health and social care and the NHS and social care sector relies heavily on the informal care that carers provide on a day to day basis. However, despite improvement over the past few years, many carers do not feel listened to,

respected or valued as a carer, which leads to frustration, stress and emotional distress. Going forward, it is vital that health and social care place greater importance on recognising the value that carers bring and treat carers as key partners.

## Recommendations

1. The Local Authority, CCG, health and social care professionals, and community sector need to continue to work together to identify hidden carers, especially young carers and the elderly, so that they can be signposted to and access support available, to help carers continue in their caring role.
2. This report found a lack of knowledge and confusion around Carers Assessments. The Carers Assessment should be actively promoted. Which would increase understanding and encourage carers to ask for an assessment if they want or need one, including those who may not have considered themselves to be a carer.
3. Promote Bexley Care Hub to increase awareness of the services available locally.
4. Carers in Bexley should be encouraged and helped by the local authority, community sector and professionals such as GPs, to put detailed plans in place for an emergency/crisis, to prevent them asking for help at crisis point and help alleviate the worry of what will happen in an emergency. Details of examples of schemes used by Barking and Dagenham and Derbyshire can be found via the following links:  
<https://www.bournemouth.gov.uk/AdultSocialCare/Carers/CarersInCrisisEmergencyBackUpScheme.aspx> <https://derbyshirecarers.co.uk/emergency-planning-derby-city>
5. For some carers the option of counselling may help them come to terms with some of their emotions, by providing a safe place where emotions can be explored in a non-judgmental way and support them in difficult situations. A review of counselling services for local carers should be undertaken to identify any gaps in service provision..
6. Further research should be undertaken to explore and understand the diverse needs and wellbeing of specific carers groups, such as those caring for a loved one with dementia, a learning disability or mental health problem. Listening to these groups of carers will help ensure that services are targeted to their specific needs which will help them continue in their caring role.

7. Explore the feasibility of the Better Care Fund supporting the implementations of this report. Specifically re emergency planning and the promotion of the help and support offered via Bexley Care Hub.

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