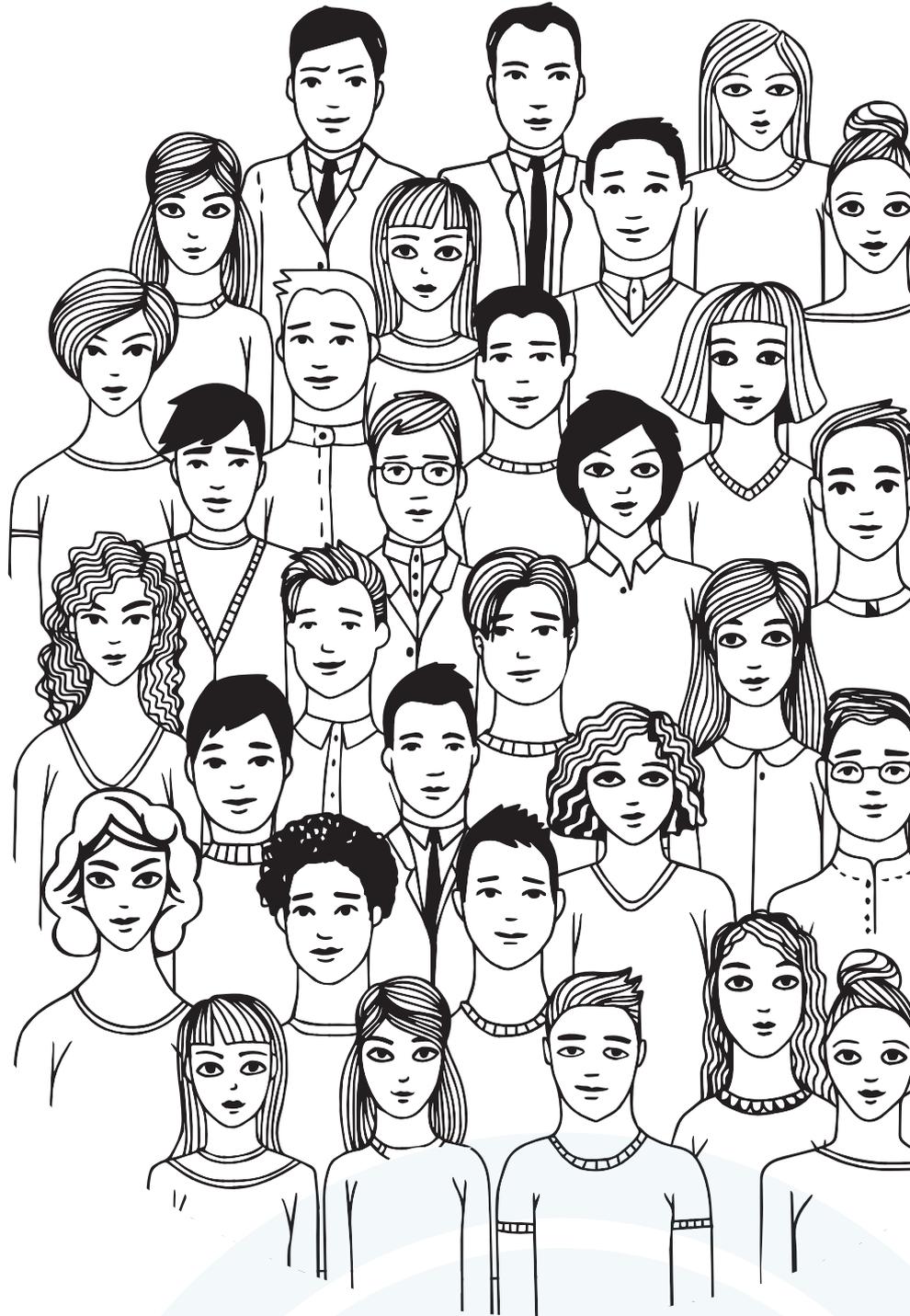


FUTURE  
CARE  
CAPITAL



## A Forgotten Army:

Coping as a Carer

## About us

Future Care Capital is a charity which undertakes research to advance ideas that will help shape future health and social care policy and deliver better outcomes for individuals living in the UK.

Beginning life as the National Nursery Examination Board in 1945, the charity has evolved throughout its 70-year history and we continue to have Her Majesty the Queen as our Royal Patron.

For further information about us, see: [www.futurecarecapital.org.uk](http://www.futurecarecapital.org.uk)

## About the contributors

The body of the present report is authored by quantitative and qualitative researchers at YouGov, based on primary research data; the foreword and recommendations presented here are authored by Future Care Capital.

The YouGov research team was comprised of Kate Gosschalk, Amelia Stevens, Briony Gunstone, Natasha Ward and Jerry Latter.

Joel Charles is the Director of Government Relations and Impact at Future Care Capital. For a large part of his career, Joel has worked in external relations across national and local government, Parliament and the third sector.

Dr Josefine Magnusson is a Senior Research Officer at Future Care Capital and brings extensive experience of public health research within a higher education setting.

## Acknowledgements

This work contains quantitative and qualitative data obtained from primary research undertaken by YouGov about the views of unpaid carers across the United Kingdom, alongside analysis of key themes and findings.

We are grateful to YouGov for leading this study and providing the robust data and insights that underpin the recommendations, made by Future Care Capital, in this report. The contribution of the unpaid carers who participated in this research and shared their experiences was enormously valuable.

Future Care Capital would also like to thank Legal & General for their kind donation in respect of the work undertaken.

 [futurecarecapital.org.uk](http://futurecarecapital.org.uk)

 @FCC\_UK

## Contents

<b>1. Foreword</b>	2
<b>2. Management Summary</b>	4
2.1 The impacts of caring	4
2.2 Support and information	6
<b>3. Methodology</b>	8
<b>4. The Impacts of Caring</b>	8
4.1 The impacts of being a carer	8
4.2 The impact on social life	11
4.3 The impact on mental health	13
4.4 The impact on family life	15
4.5 The impact on finances	17
4.6 The impact on work	21
4.7 The impact on physical health	22
4.8 The impact on education	24
4.9 Preferences for continuing higher education	27
<b>5. Support and information</b>	31
5.1 Support	31
5.2 Training	38
5.3 Technology	40
<b>6. Future outlook</b>	43
<b>7. Conclusions</b>	44
<b>8. Future Care Capital's recommendations</b>	45
<b>Appendix A – Breakdown of responses</b>	47
<b>Appendix B – Age summary</b>	49

## 1. Foreword

There are almost eight million informal carers in the UK. Their efforts are a big part of the way that we, as a society, look after people. A recent estimate valued the contribution of informal carers at £140bn – nearly the same size as the National Health Service.

But the impact of informal carers is much deeper than that. In 2015 a study by Monitor showed that, for older adults, “10 days of bed rest led to a 14% reduction in leg and hip muscle strength and a 12% reduction in aerobic capacity: the equivalent of 10 years of life”. Carers are important because they help people to get the right kind of support in the right environment.

At Legal & General we have supported our customers’ financial resilience for nearly 200 years; and we understand that we have a social as well as an economic purpose. Every generation faces its challenges and we see the challenge of our time is to ensure that we support the NHS and carers to continue to be the bonds holding our society together.

This research about carers is important because it tells us more about the needs of millions of people who are holding together the social contract that underpins our society.

Carers are delivering the intergenerational contract; their work supports the NHS; their work supports the long-term care system and, of course, their love and work holds together millions of families. That is why we, as a society, need to find more and better ways to ensure that carers have the support they need to do what they do.

There is a healthy and long-running debate about how the country best supports people who need long-term care and their carers. We are contributing to this debate, but we also think it is important to ‘get on and do’, where we can make a difference.

The focus of the debate about long-term care is often residential care. Care in residential communities is a crucial part of the overall system but we should not forget that there are millions of people who are cared for at home. By 2036 there will be more than 5m people aged over 80 in the UK and meeting their care needs will require a focus on the care-at-home market – we know from research and our customers that people want to stay in their own homes for as long as is possible. To do this, there are going to be millions of carers – both formal and informal – who will need support. To indicate the scale of the challenge already: in 2018 there were 1.8 million requests for adult social care support from 1.3 million new clients.

That is why we are taking action now to help the NHS, the government, carers and the people they care for. At the heart of the provision of long-term care there is an imbalance in supply and demand for care that we are working to address. Addressing the supply side of the sector is important and a long-term goal, however we can act quickly by using innovative technology to better allocate demand.

Understanding carers’ needs is a crucial addition to the debate about how we support people who need long-term care. The cost of not getting the system right is high: older people, particularly, lose mobility very quickly if they do not keep active. That is why we supported this research and why we will take its conclusions seriously as we think about how to support our customers in the years ahead.

**Steve Ellis,**  
**CEO of Legal & General Retirement Living Solutions**

## 2. Management Summary

### The impacts of caring

The impacts of being a carer are wide ranging and for many carers, the role affects all aspects of day to day life. Carers were most likely to feel the effect of caring on their social life, with close to two thirds (64%) reporting an impact on this as a result of their caring role, followed by their mental health (49%) and family life (45%).

The qualitative phase suggests that there is a great deal of interaction between the areas of life that are impacted, with feelings of social isolation feeding into poor mental health, which can lead to poor physical health; all of which can contribute to financial strain.

### Social life

Social life is the area that carers were most likely to mention the impact of caring, with close to two in three (64%) carers reporting this. This is most commonly a result of having less time to themselves (48%), socialising less (47%) and generally having less contact with others (41%). Unsurprisingly, full time carers (30 or more hours per week) were most likely to report an impact on their social life.

In addition to a lack of free time, in the qualitative phase carers mentioned that when they did find time to socialise, they felt guilty about not being there for the person they care for, worry about what is happening at home without them there, and cannot fully relax or enjoy themselves.

### Mental health

Half (49%) of carers mentioned the impact of caring on their mental health. The most common impacts were increased stress (42%), anxiety (33%) and depression (27%).

It was most common for carers with a close familial relationship with the person they care for to report an impact on their mental health, rising to three in five (62%) of carers for their child. In the qualitative phase, parents caring for children with autism or other disabilities emphasised that their child's future independence and caring for them beyond this was a significant worry for them, only adding to the overall stress felt as a result of caring.

### Family life

Close to half (45%) mention impacts of caring on their family life, most notably spending less time with family and not getting to go on family holidays (19%), followed by more arguments and spending less time with their partner / spouse (17%).

Women were more likely than men report an impact on their family life due to their caring role (47% vs. 42%) which can stem from feeling less able to look after children and dependents (14% vs. 9%) or spending less time with their partner / spouse (19% vs. 15%).

### Finances

Over two in five (44%) carers note the impact of caring on their financial situation. This is mostly due to having less money due to reduced or no work and an increased spending associated with caring (both 27%). Carers who offer help and support for a child were particularly likely to report

that caring has affected their financial situation (62%).

The qualitative phase revealed many hidden costs of caring, including paying for medical supplies, transport to and from appointments, maintaining a healthy diet and paying for doctors notes. Other costs included having to buy vital home adaptations, such as wet rooms and chair lifts, with carers mentioning the financial sacrifices that have had to be made in order to provide care.

### Impact on work

There was an effect on working life for two in five (42%) carers. For close to one in five (18%) this is due to having to stop working all together, whilst approximately one in ten said they had to work reduced or flexible hours, or had decreased performance at work e.g. difficulty concentrating.

This was mirrored in the findings from the qualitative phase, with carers noting the importance of employers being flexible and permitting them to work around their caring responsibilities, as well as the impact that emotional strain can have in the workplace.

### Physical health

Two in five carers reported an impact of caring on their physical health, most often mentioning tiredness (35%), trouble sleeping (28%) and reduced fitness (20%) as the areas of their physical health that had been affected.

Carers who had been caring for more than ten years were more likely to report an impact on their physical health. Impacts were also greater for carers aged 50 and over, who were more likely than average to report feeling tired and back pain. This finding was mirrored in the qualitative phase, where older carers spoke of experiencing increasing difficulty fulfilling their caring role over time, stemming from decline in their own health as they aged.

### Impact on education

Likely related to the age of many carers, education and training is the area where caring is least likely to have had an impact (12%).

An impact in this area was unsurprisingly more likely for younger carers, with three in ten carers aged 16-34 saying that their education or training had been affected. This also came out of the qualitative interviews whereby young participants mentioned having to complete homework late at night, negotiate extensions to school deadlines, retake exams and having to defer/delay university education.

Around a quarter of carers (27%) mentioned that there was at least one type of further / higher education that they would have liked to partake in, but could not, due to their caring responsibilities.

### Preferences for continuing education

Overall, approximately a third (36%) of carers reported having an interest in starting or continuing further or higher education, though a larger proportion (57%) did not. Yet whilst an interest exists, many barriers also do. Among carers that would be interested, almost three quarters (72%) reference cost as a barrier, with a sizable proportion (62%) reporting that their caring responsibilities were a deterrent in themselves.

When thinking about the preferable ways of learning whilst continuing in their role as a carer, half said that e-learning in the form of online tutorials would be their preferred way of learning, with part time study being the next most favoured option (30%). E-learning is likely popular due to its accessibility, meaning that carers could access it in their own time and it can therefore fit around other commitments.

## Support and information

### Support

Around half of carers said that they had received some form of information or support to assist with their role as a carer. Most commonly, this was access to equipment such as stair lifts or adaptations (17%) or information on the support available to carers (16%). Carers of someone aged up to 19 were more likely to have received various types of support.

The qualitative findings also suggest that many carers had not received support at all, stemming from a lack of knowledge of who and where to go to, and not knowing at what point of the journey they become eligible for support.

A sizable majority (74%) of carers felt that (further) support in some form would be useful to them, with a common desire for emotional support (33%). Following this, carers were keen for information and advice on the support available, respite care, and financial advice and information.

Carers of middle age were more likely to say that they want additional support, compared with their younger and older counterparts. In line with earlier findings, carers who provide greater amounts of care were more likely to say that additional support might be useful to them – but even among carers providing under 10 hours of care, a sizable proportion (70%) mentioned one or more type of support that would be useful to them.

When thinking about how carers would like to receive this support, face-to-face with a support worker or trainer was preferable for over two in five (44%) of those wanting support. Around a quarter of this group mentioned receiving support online via a website or e-learning platform, printed materials, and an online support forum. This varied by age, with younger carers aged 16-34 more likely to mention wanting to receive support via an app, whilst carers aged 65+ were most keen for face-to-face support.

Yet the qualitative phase suggests that many carers had not received support at all, stemming from a lack of knowledge of who and where to go to, and not knowing at what point of the journey they become eligible for support.

### Training

Overall, the findings show that 13% of carers had received some form of advice or training in relation to their role as a carer. Most commonly this was training in medical tasks, advice on their own mental/emotional health, and training in giving emotional support to the person cared for (each 3%).

Reflecting the low proportion of carers that reported having already received specific training or advice in relation to caring, a larger proportion (27%) indicated that some form of advice or training would be useful to them. Younger carers and those in the middle age years were more likely to state this, along with carers who devote greater amount of times to their caring responsibilities.

The qualitative phase also found that there was a need for advice on mental and emotional health, shining a light on the often unexpected levels of stress, isolation and despondency that being a carer can lead to.

### Technology

Although there is a growing world of technology that can make the caring role considerably easier, only one in three (33%) carers reported using technology to assist with their role as a carer. This also came out of the qualitative interviews where carers were unlikely to spontaneously mention having used technology.

Carers were most likely to have used medication aids, with one in ten saying they have used them to assist with their role as a carer. Following this, remote monitoring aids (8%) and online / remote advice, automated prompts and reminders and smart home technology (all 7%) are the next most commonly used types of technology. Often early adopters of technology, young people were more likely to have used technology in their caring role.

## Future Care Capital summary note

There is an opportunity to address the impacts on carers that are identified by this research and to put in place additional support so that unpaid carers do not reach breaking point, where they are unable to cope with the pressures they must manage daily. There are five recommendations that are set out in the concluding section of this report, made by Future Care Capital. The recommendations focus on carers identification and signposting, greater educational flexibility, training and support, tackling hidden costs and enhancing carers rights.

This report aims to add to the existing weight of evidence and contribute to the debate about the rights and support made available to unpaid carers. Following the publication of this research, Future Care Capital aims to collaborate with key stakeholders and engage the Government in a conversation about how to deliver better targeted support.

### 3. Methodology

The survey was carried out online using the YouGov panel between 1st February and 21st February 2019. The total number of responses was 2,217 unpaid carers and the data was weighted to be representative by gender, age, region and ethnicity.

20x respondents were selected from the survey completes to participate in a 45-60 minute face to face interview, 3 of which were filmed. A range of demographics were incorporated into the qualitative phase, including a mix of age, location, social grade, gender, ethnicity and sexual orientation. 14x participants then went on to complete one of 2x 90 minute online focus groups.

Throughout the report, we highlight interesting differences between sub-groups where these are significantly different than could be expected by chance ( $p < 0.05$ ).

Where '\*' appears next to case studies and quotations, participants' names have been changed to protect their identities.

Further details of the respondent breakdown within the data can be found in Appendix A.

### 4. The Impacts of Caring

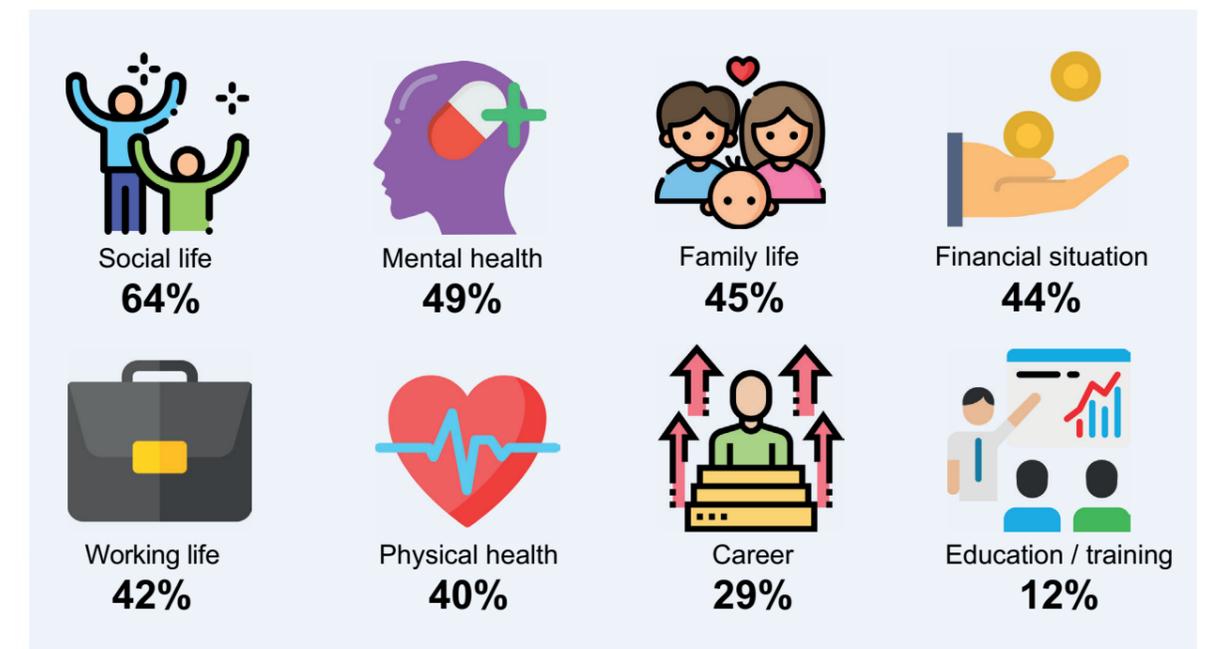
#### The impacts of being a carer

For many carers, caring has a profound impact on all aspects of day to day life. From having less time to themselves, struggling with physical and mental health and needing to stop working or work reduced hours, the impacts of taking on a caring role are varied and unique.

*"I don't do anything for myself anymore, my health has worsened and my confidence has been shattered." – F, 44, cares for mother*

Carers were most likely to report an impact on their social life (64%), followed by their mental health (49%) and family life (45%). Education and training is the area where caring is least likely to have had an impact, with only one in ten (12%) saying this.

Figure 1: Impacts of caring on different aspects of life



It is clear from the qualitative phase that there is a great deal of interaction between the areas of life that are impacted by providing unpaid care, and these interactions ultimately work to exacerbate the stress felt by carers overall. For example, inability to work full time leads to financial strain, which in turn contributes to isolation due to the cost associated with social occasions and getting out and about. Social isolation feeds into poor mental health, which can then impact negatively on physical health in the form of inadequate sleep and comfort eating. Poor mental and physical health are noted by some participants to have an additional impact on their ability to work, again contributing to financial strain. Although many of the carers we spoke to were able to objectively recognise the impact of caring on their own lives, a majority also described compartmentalising their problems and stresses in order to cope day to day; few see any alternative to their current situation, and so they try not to consider the impact of unpaid care too deeply.

*"You just get on and do it because you have to." – M, 61, cares for father*

*"These are all things I try not to think about!" – F, 18, cares for father*

### Harminder is 42 and has been a carer for her mother for the last 2 years

Her mother suffers with dementia and osteoarthritis. Due to her mother's reduced mobility and poor condition of her bones and joints, Harminder assists her mother in all activities of her day to day life, including helping her to the bathroom, cleaning, cooking and moving her around the house.

Harminder worries about her mother falling and hurting herself, as she has done before, so she sleeps on the sofa in the lounge, next to her mother who sleeps on a hospital bed. She describes herself as feeling exhausted and burnt out; her sleep is very poor as she feels she is 'on alert' all the time, and she does not get any time away for herself.

Harminder has recently had to reduce her working hours due to the combined stress of working and caring. She says this cannot be a permanent arrangement, and worries about what will happen when she returns to work full time. She has considered changing her job to one which is less emotionally challenging but says this would be 'heartbreaking'. She doesn't like to think about the future and says she's 'not too optimistic'.

Harminder does not tend to socialise; she says she finds caring draining and cannot financially afford to attend social events. She has also felt judged in the past by friends and has fallen out of contact with them, and so tends not to open up about her experiences as a carer. She explains that, even if she were able to go out and see friends, she would be worrying about her mother and unable to switch off. Harminder is reluctant to employ private care; as her mother is not fluent in English, Harminder worries about finding a carer able to communicate properly with her mother and fully understand her needs.

She would like support to be more forthcoming from the state and feels that charities have to 'pick up the pieces'. She has tried to contact support organisations in the past to help with her caring responsibilities but has never heard back from them. She applied for carers allowance recently, however the wait for a decision was long and she was frustrated to find she did not qualify for financial support. Currently, Harminder pays for home adaptations and mobility aids for her mother privately, and feels this restricts her ability to save up for her own future.



*"I was just feeling like my head was constantly overwhelmed with thoughts, at night I wouldn't sleep properly because I'd constantly be thinking about the next day."*

*"I don't think about the future now, I just get on with what I've got to do...just day by day really."*

## The impact on social life

It is most common for carers to feel that their caring role has impacted their social life, with close to two thirds (64%) reporting this. Having less time to themselves (48%), socialising less (47%) and generally having less contact with others (41%) are the most mentioned reasons for feeling this way, suggesting that the role can leave carers with feelings of isolation and loneliness.

*"For me the worst part is the isolation, I wish I could get out and meet people but at present I can't." – F, 62, cares for mother*

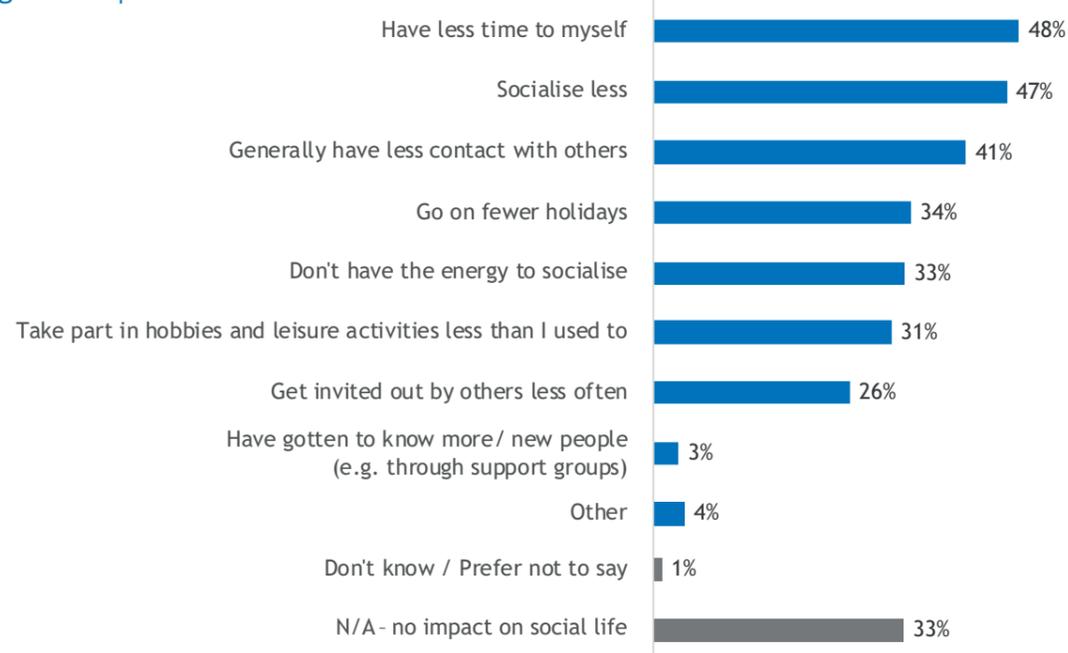
Unsurprisingly, carers who provide full time care (30 or more hours per week) were most likely to report their social life being impacted as a result of their caring role with the majority (72%) mentioning this, compared to half (51%) of those caring for less than 10 hours per week. For many, the continuous care they provide results in them socialising less (59%), having less time for themselves (57%) and generally having less contact with others (55%).

The impact of caring on social life can be seen in emotional barriers as well as practical ones; although many of the people we spoke to in the qualitative phase mentioned lack of free time and respite support as a significant challenge to their social lives, many also noted that on the occasions they do get time away to socialise, they feel guilty about not being there for the person they care for, worry about what is happening at home without them there, and cannot fully relax or enjoy themselves.

*"Right up until the time I went [on holiday] I didn't want to go...I didn't want my mum to have to deal with everything on her own, so I felt really bad for going." – F, 23, cares for sister and grandmother*

In general, carers aged 35 and over were more likely than their younger counterparts (aged 34 and under) to say they have experienced the impacts on their social life (67% vs. 52%). They were more likely to say they have less time to themselves (51% vs. 38%), socialise less (49% vs. 37%), generally have less contact with others (45% vs. 37%) and go on fewer holidays (36% vs. 15%) – amongst other impacts. Younger carers aged 16-24 were most likely to say there has been no impact on their social life, with 42% reporting this.

Figure 2: Impacts on social life



Base: all unpaid carers (n=2,217)

Carers that provide help and support for someone with multiple comorbidities were more likely than average to say they have less time to themselves (54% vs. 48%). This could be a result of the complex nature of caring for someone with multiple needs, which is likely to be time consuming and tiring.

Women were more likely than men to say that they have less time to themselves as a result of caring (51% vs. 45%), and that they do not have the energy to socialise (37% vs. 28%).

When speaking with a number of carers, it was highlighted that in addition to being short of time to socialise, they also have the challenge of overcoming judgement and a lack of understanding. Although many described their friends as being outwardly supportive, some felt that they could not really understand what they were dealing with and said that they tend to keep the caring side of their lives private. Some also felt that they had lost friends as a result of their caring responsibilities taking up much of their time.

*"I lost one friend in particular who said that I was using my mum as an excuse and not putting myself first and it's not that bad of a situation..."*

*relationships have been impacted, [I've] been told I have 'too much baggage' which is awful"*  
**- F, 23, cares for parents**

Carers who give help and support to their parent were more likely to say that caring has not impacted their social life than those caring for a child (36% vs. 26%).

## The impact on mental health

Half (49%) of all carers reported that their mental health has been affected by providing care for another person, with this figure being the second most common impact upon the lives of carers in general, after a decline in their social lives (64%). This was most likely due to increased stress (42%), anxiety (33%) and depression (27%). Very few reported feeling a sense of purpose as a result of caring (8%) or commented that they had subsequently become more resistant to other challenges (7%).

Unsurprisingly, affected mental health was most common among those with a close familial relationship with the person they are providing care for, whether that is a parent (49%), spouse (46%) or child (62%). The duration of care played a part in the likelihood of the carer to feel an impact, with those caring for 30 or more hours per week being significantly more likely to experience mental health issues (at 54% compared to 45% of those caring for less than 30 hours per week).

Those caring for people aged 18 and under were the most likely to feel an impact on their mental health, with two thirds (67%) reporting that this was an area of their life affected by caring. Many of the parents we spoke to who were caring for children with autism or other disabilities highlighted that their child's future independence (and how to care for them into adulthood) was a significant worry for them, adding to the overall stress felt as a result of caring.

*"In some ways he gets more demanding [as he gets older] - because now there is a lot of ability to control him physically, but he will get stronger...and you worry that he might not always be around you when he's older, so he might be abused by other people."*  
**- F, 48, caring for son**

Carers of people with predominantly non-physical health conditions were most likely to experience mental health issues themselves, particularly if the person they are providing care for suffers from autism (67%), addiction (67%) or mental health conditions (66%). Those providing palliative care were also significantly more likely than some to experience an impact on their own mental health (57%), perhaps due to feeling that their efforts are somewhat in vain, as the person they are caring for has a terminal prognosis.

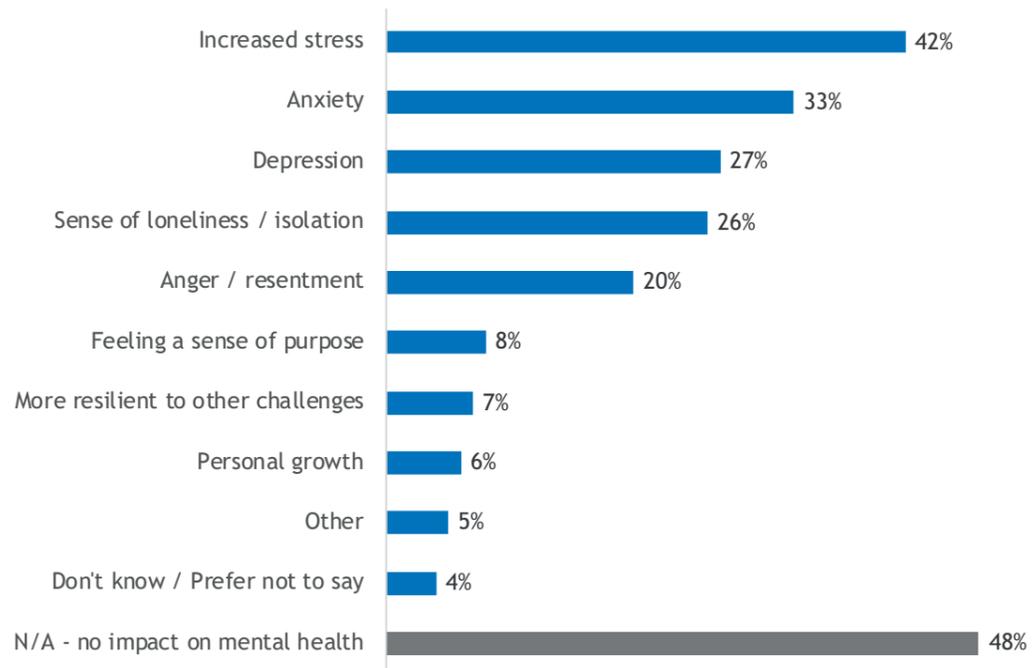
*"Very frustrating to see that your best efforts can't really halt the slide towards the inevitable."*  
**- M, 46, cares for mother**

It is important to note, however, that even those caring for someone with a primarily physical disability or condition often felt relied on for emotional support; arguably, the pressure to provide holistic support on such a consistent basis adds to the overall feeling of burnout experienced by some of the carers we spoke to.

*"There are physical aspects and mental aspects, so it's a double whammy."*  
**- F, 62, cares for spouse**

*"The emotional has more of an impact as you need to be positive and soldier on for everyone's sake."*  
**- M, 63, cares for spouse**

**Figure 3: Impacts on mental health**



Base: all unpaid carers (n=2,217)

Women were more likely than men to report many of the aspects of mental health, such as increased stress (46% vs. 37%), anxiety (37% vs. 27%), depression (30% vs. 23%) and a sense of loneliness / isolation (30% vs. 21%).

Half (51%) of carers aged 35-49 reported increased stress, higher than the stress levels of younger carers aged 16-24 (32%). Carers of this age were also more likely to mention anxiety (40% vs. 27%) and depression (34% vs. 24%), amongst other impacts.

Those providing help and support for someone with autism (61%) were most likely to mention feeling increased stress as a result of their caring role, as were those caring for someone with a mental health condition (57%). Often carers of people with these conditions provide large amounts of weekly care, hence it is unsurprising that they feel the effects of the role.

The carers we spoke to in the qualitative phase frequently mentioned limited opportunity for formal or informal respite, making self-care difficult; it was clear that for the majority, their own needs took a back seat. This was apparent not only in the carers' own approach to their wellbeing, but also in terms of the services made available to them; few of the carers we spoke to in the qualitative phase had been involved with professional services to support them with their own mental wellbeing, and those who had tended to feel the support received was inadequate.

*"It would be good if their [services] were better equipped to know when something's wrong and know when someone needs support, not just waiting for someone to breakdown...if [support] is short term then you feel like you're getting a lot of support in a short space of time then you feel very isolated after." - F, 18, cares for father*

Many of the carers we spoke to also felt that there was little point in opening up about the emotional toll of caring; reasons for this include needing to stay strong for the person they are caring for and feeling that their situation cannot be helped.

*"I think it's the emotional and the mental - you are yourself struggling but it's your duty, you have to do it." - F, 52, cares for mother*

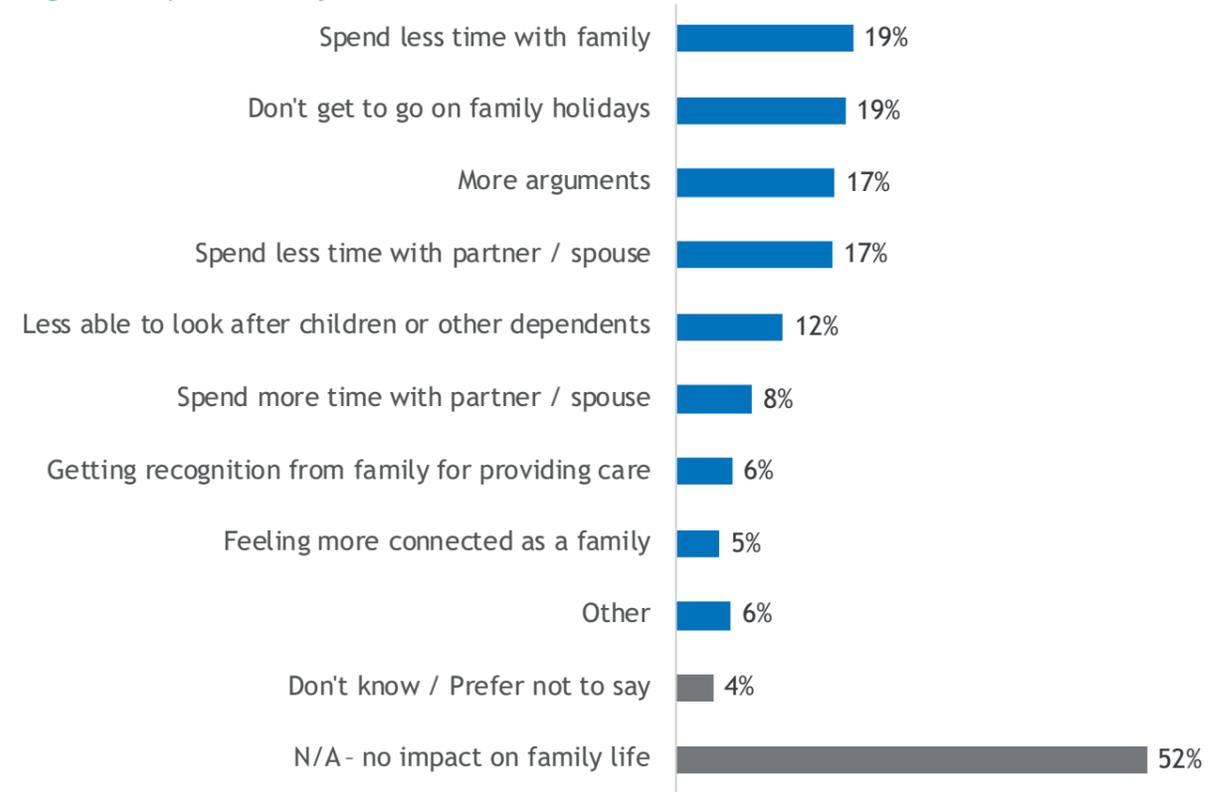
*"I suppress the emotional side of things because if I let them out it would destroy me...so I cannot afford to let emotions take hold." - M, 53, cares for spouse*

### The impact on family life

Forty five percent of carers said that being a carer has had an impact on their family life. Spending less time with family and not getting to go on family holidays (19%) are the impacts most commonly mentioned, followed by more arguments and spending less time with their partner / spouse (17%).

Women were more likely than men to say that their family life has been impacted as a result of being a carer (47% vs. 42%). This is due to them feeling less able to look after children or dependents (14% vs. 9%), noting more arguments (19% vs. 15%) and spending less time with their partner / spouse (19% vs. 15%).

**Figure 4: Impact on family life**



Base: all unpaid carers (n=2,217)

Young carers aged 16-24 were least likely to say that caring has impacted their family life (25% compared to 47% of carers aged 35 and over), though this might be a result of them not knowing their family life any differently. Many young carers provide help and support for a parent and the impact of this on their family situation will likely manifest itself in different ways to that of older carers who might be providing care for children or their partner / spouse.

Carers aged 65+ were the age group most likely to say that they spend more time with their partner / spouse as a result of being a carer (14%), which could be a result of this age group being more likely to say they care for this person.

Caring for a young person (aged 19 or less) has a profound impact on the time spent with a partner / spouse, with two in five (41%) of those providing care for young people citing this as an impact.

As with the impacts previously mentioned, carers who provide 30 or more hours of care per week were most likely to report the impact of caring on their family life (47% vs. 39% of those caring for less than 10 hours a week). A quarter said they do not get to go on family holidays and a similar proportion (23%) reported they spend less time with family.

The qualitative interviews highlight that informal caring can have an impact on family life, which manifests in a number of ways. As many are caring for family members, very often this involves spending more time with them, but that is not always to say that this leads to harmonious relationships. Participants sometimes observed that familiarity can breed contempt, often due to the demands placed on the carer by those they are caring for, but it tended to be more the case that the person in receipt of care is grateful for the other person's time and effort.

Some of the interviews conducted were with mothers of children with autism, and this often created a unique set of circumstances. To varying extents, the children had challenging behaviour patterns anyway (one child had pulled a knife on his mother and the police had to be called), and spending so much time together often meant that unpredictable and erratic behaviour was able to come to the fore, and put strain on the family dynamic. That said, for all of these parents, their presence provided a vital crux for the child(ren) who relied on them for emotional support, so the time they spent together benefited the child and helped to quell some of the problematic behaviour.

In other interviews the strain on the family was shown in less overt ways – the participant who flew from London to Scotland to intermittently care for his mother did not feel that his actions had any impact on the relationship with his wife, but she begged to differ, claiming in the interview that her loneliness during his absence has brought her to the brink of despair, and that the caring responsibilities had taken their toll on his mental health.

*“Emotionally, I don't feel that I've taken a direct hit, but my wife begs to differ”  
– M, 40, cares for mother*

Many of the qualitative interviews highlighted the need for relationship management, when relationships between the carer and the caree had broken down, or when difficult conversations (for example around the future) were not forthcoming. It might also be the case that such

relationship management could, through encouraging an honest dialogue, help to manage the expectations of the caree, which often went above and beyond what the carer was realistically able to provide.

*“She can do certain things but when I am around she goes out of her way to make out she can't do anything. If visitors come she over exaggerates things to make it look like I don't do anything else for her and that doesn't help my condition.” – F, 52, cares for mother*

## The impact on finances

The same proportion (44%) of carers said that being a carer has had an impact on their financial situation. Most notably, around a quarter (27%) reported having less money due to reduced or no work, and the same proportion note an increased spending associated with caring. For some, this increased spending includes paying out for vital home adaptations such as wet rooms, stair lifts, hand rails and other aids/equipment. While some mentioned that they have applied for financial support for such adaptations from the local authority, only a minority have been successful, with others having to save up to foot the full cost themselves or missing out on adaptations altogether.

*“We are struggling in our house now so we have just recently had a stair lift fitted (again paid for privately as any support was declined). We ideally need a downstairs wash room but the cost and work involved would be too much.” – F, 44, cares for mother*

The qualitative interviews certainly bear this out, with a strong sense amongst those who took part that sacrifices have had to be made in order to provide care. Many have had to leave work, and do so unwillingly, as their full time employment provided both a means to support their family and a sense of identity. Even when the care that was provided was relatively 'light-touch', such as parents who care for their autistic children, there was still a sense that it was impossible to work full time because of the emotional demands that the children place on them.

*“Financially, I am currently living off carers' allowance, 64ish pounds a week. Living with my parents saves on rent and bills but now being able to run a car means fuel. Insurance etc which is hard. I have no money but all my friends often want to go out for meals which I often turn down as I can't afford.” – F, 23, cares for Mother*

This loss of work had led to, in one case, a family having to downsize to a much smaller home, and, in another case, for a family to move town altogether to an area where the living costs were cheaper. But even in the less common cases where participants had not had to give up work, they had had to make other sacrifices – one participant was flying up to Scotland from London every few weeks to provide physical care for his mother, who was housebound through arthritis and dementia. The cost of this was eating up much of his annual leave entitlement and

discretionary spending.

During the qualitative phase, participants also highlighted hidden costs of caring as having a further impact on their financial situations; having to pay for medical supplies/aids and transport to and from appointments were mentioned, as well as additional electricity and heating costs. Some also spoke about the cost of maintaining a healthy diet (low sugar, low fat etc.) in line with medical advice, which can be expensive due to the greater cost of fresh fruit, vegetables and 'free-from' items in comparison to other foods. It was also noted by participants that applications for support (e.g. carers' allowance) also have costs associated, such as paying for doctors notes, postage and printing.

*"We had to pay to get a doctor's letter that was about two sentences long and cost about £40."  
- F, 23, cares for parents*

*"Because of his heart condition he has to follow a [special] diet. Of course, anything that is highly nutritious but low in calories and low in sugar, low in fat, costs more money...so the cost of [good] food is a big part of what we spend each month." - F, 62, cares for spouse*

Speaking to people during the qualitative stage, it was clear that many feel frustrated with the state financial support available. Those who do receive carers' allowance said that the amount received is minimal, particularly if they then have deductions made to other benefits as a result. Furthermore, a number of people spoken to had previously applied for carers allowance but had been turned down, which many did not understand given the amount of support they provide, and the subsequent impact of this on their own finances (e.g. hidden costs and inability to work full time). An additional issue came to light when speaking to a young carer who found that she was unable to claim carer's allowance whilst attending university (despite having continued to live at home to support her parents). Overall, there is a feeling of frustration over the perceived lack of support provided; many feel that financial support is a right, given that provision of unpaid care ultimately saves the state money.

*"I claim carer's allowance - a paltry sum even less than universal credit per week - and the authorities consequently remove that amount from the disabled benefit my husband receives so as a married couple I am effectively unpaid." - F, 62, cares for spouse*

*"It also is restricted in you can't study full time and get carers allowance despite it clearly being possible. The amount that is paid is a joke, I mean I appreciate it but it is totally a joke."  
- F, 23, cares for parents*

Carers looking after their child were particularly likely to report that caring has affected their financial situation, with three in five (62%) having mentioned this. Many parents will have had to care for their child for a number of years, and the pronounced impact on their financial situation is likely a result of continuous spending associated with caring. They are also likely to be offering

full time care (60% care for 30 hours or more a week) which too will have additional costs associated with it. Parents providing care for their children are also more likely to say they have less money due to no work and note the increase in their spending associated with caring, with three in five reporting this.

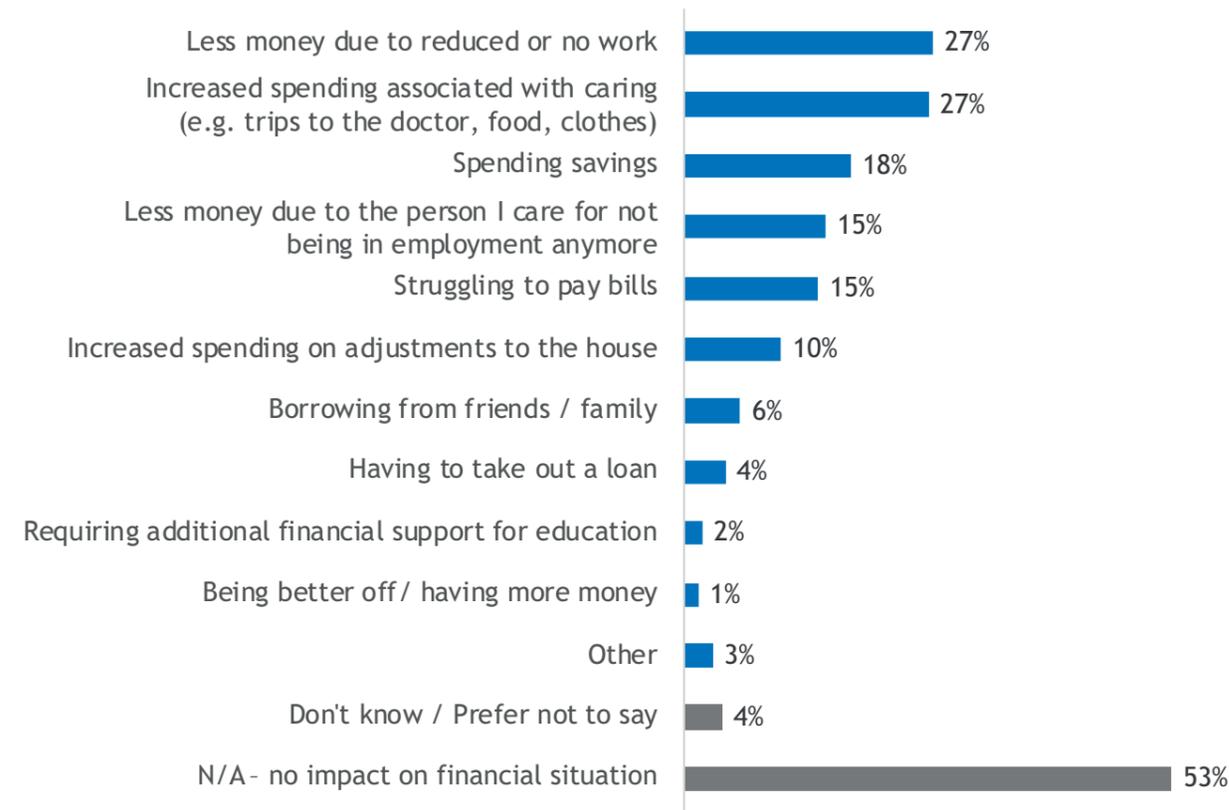
Some participants in the qualitative phase caring for children with learning disabilities/autism described increased spend on clothing, particularly school uniform, as a result of loss or damage; one also noted that transport costs are high as their child is unable to travel independently (e.g. walking to school, taking public transport), as other children their age would be able to.

*"My son loses/damages a lot of his possessions so there is an additional cost involved in this too."  
- F, 36, cares for son*

As with the impacts on both physical and mental health, there is a correlation between time spent caring per week and the impact on ones' financial situation; whilst just a quarter (26%) of those providing care for less than 10 hours a week reported an impact on their financial situation, over half (57%) of those providing care for 30 or more hours mentioned this. For each of the impacts on carers' financial situations, those who provide higher amounts of care each week were more likely to report them.

Younger carers aged 16-34 were more likely than those aged 65+ to report having less money

**Figure 5: Impacts on financial situation**



Base: all unpaid carers (n=2,217)

## Case study - Beth

### Beth\* is 23 and has been a carer for her mother and father for 13 years

Beth's father has mental health issues, and her mother has mobility issues and chronic pain following an accident.

Beth looks after the cooking, cleaning and finances in her house, as well as caring for her parents' medical needs, such as changing dressings on her mum's legs.

Beth lives in a small flat with her mum, dad and older sister. Both of Beth's parents are unable to work due to their respective health conditions and her family relies on disability benefits as their main income. Beth suffers with fibromyalgia herself, and also emphasizes the need for flexible working hours to allow her to continue to care for her parents; these constraints further add to the family's financial difficulties as Beth is not currently able to work.

Beth currently receives carers allowance, which helps her to keep things 'ticking along' at home, however she was only able to receive this once she had finished university, despite continuing to be a full time carer to her parents during her studies. She describes the process of applying for financial support as 'crazy' and says that, especially as a young carer, it is difficult to figure out what to do with all of the forms needed.

Beth says that her family have experienced difficulty in the past getting essential household items fixed, and have had to apply for help from local charities on several occasions. She also mentions that, if her parents need to go to appointments, transport can become an additional expense if they are too unwell to take public transport.

In Beth's view the local authority could do more to help with their living situation – while Beth was able to successfully apply to have an outside toilet and a wet room fitted, the handrails around their home have been broken for 'years' and the council have provided no assistance to fix them.

For Beth, some of the best help that could be offered would be education around finance and applications for grants: how to fill out forms and understanding what carers are entitled to.



*"We were having to use taxis when it was really bad, because you didn't want [mum] to get the bus; but then it's the cost of it, so you're pulling at strings to try and afford it, and you don't want to not afford it. You're drained of constantly having to sort it out."*

*"If something breaks... it's going to have to stay broken for a long period of time... the boiler was broken for like a year or two."*

due to reduced or no work (17% vs. 11%), though older carers were more likely to say there has been an increase in spending associated with caring (21% vs. 13% of 16-24 year olds).

The impact of having less money due to reduced or no work is particularly felt by carers who provide 30 hours or more per week, with two in five (42%) citing this, compared to one in ten of those caring for less than 10 hours a week.

Just over half (53%) of carers reported that caring has not impacted their financial situation. This is more prominent amongst young people, with two-thirds (66%) of 16-24 year olds saying this. Carers that do not live in the same home as the person they care for were less likely to feel an impact on their finances, with 63% saying there has not been an impact on their financial situation, compared to half (47%) of those that live with the person they care for.

## The impact on work

Two in five (42%) carers said that their role has had an impact on their working life. Close to one in five (18%) reported having to stop working all together, whilst approximately one in ten said they had to work reduced (12%) or flexible hours (11%) or had decreased performance at work e.g. difficulty concentrating (11%).

This was also reflected in the qualitative responses, with many carers explaining that employer flexibility is vital in order to work around their caring responsibilities, and highlighting the impact that emotional strain can have on resilience in the workplace. Key challenges to maintaining full time work were appointments and accidents/fluctuations in the health and ability of the person being cared for.

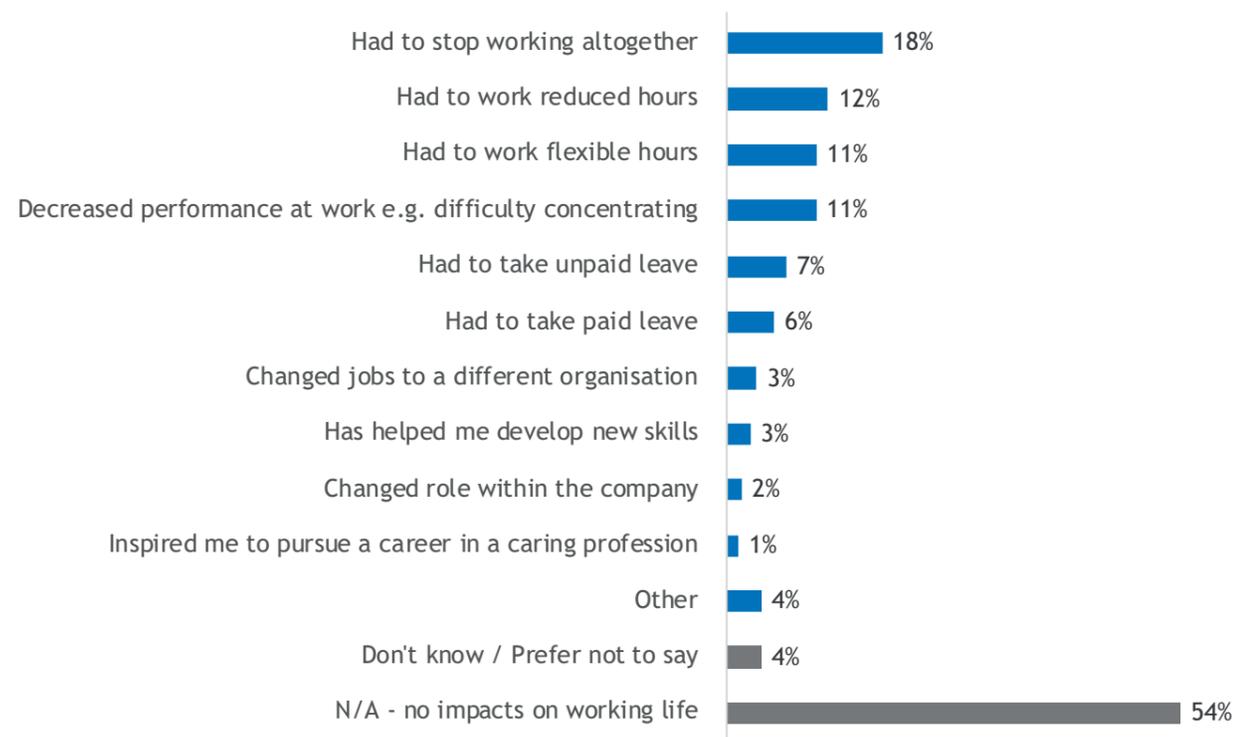
*"If I had a work obligation and then he phones to say he's had an emergency...well it just wasn't working very well." – F, 62, cares for spouse*

*"I am lucky that I can be flexible with my work but it has been difficult juggling appointments." – M, 61, cares for father*

Carers aged 35-49 were most likely to report an impact on their working life, with over half (55%) saying caring had affected their work, compared to close to a third (30%) of carers aged 16-24 and one in five (19%) of those aged 65+. This is likely to be a result of these groups being less likely to be in full or part time employment due to their age. Having to stop working all together was most common among carers aged 35-64 with 23% reporting this, compared to one in ten of those aged 16-24 or 65+ (9% and 10%).

Carers providing help and support for their child are also more likely to have had to stop working, as are carers for someone with autism (30% and 31% respectively). Carers that look after people with these conditions are likely to be providing vast amounts of care each week (30

**Figure 6: Impacts on work**



**Base: all unpaid carers (n=2,217)**

or more hours) which mirrors the hours of a full time job, therefore it is unsurprising that many have had to give up work. Furthermore, during the qualitative phase, some carers providing care for a child/young person also noted the difficulty of securing reliable childcare outside of school hours, which acts as a further barrier to employment.

*“Other people with children his age can make use of before and after school clubs, so they can work better, but I cannot do that...people tend to not want to have that extra responsibility of his behaviour and his personal care issues.” – F, 48, cares for child*

Carers who provide support for less than 10 hours a week were most likely to say that their role has not had an impact on their work life, with two-thirds (68%) reporting this, compared to under half (43%) of those caring for 30 or more hours a week.

Carers with an interest in further / higher education were more likely than those without to say they had to stop working all together (25% vs. 15%), had to work reduced hours (17% vs. 9%) or had to work flexible hours (14% vs. 9%), possibly suggesting there is a link between having to stop work or work reduced hours and having a desire to continue in education.

## The impact on physical health

A similar proportion (40%) of carers reported that their physical health has been affected by caring, with tiredness (35%), trouble sleeping (28%), reduced fitness (20%) and back pain (18%)

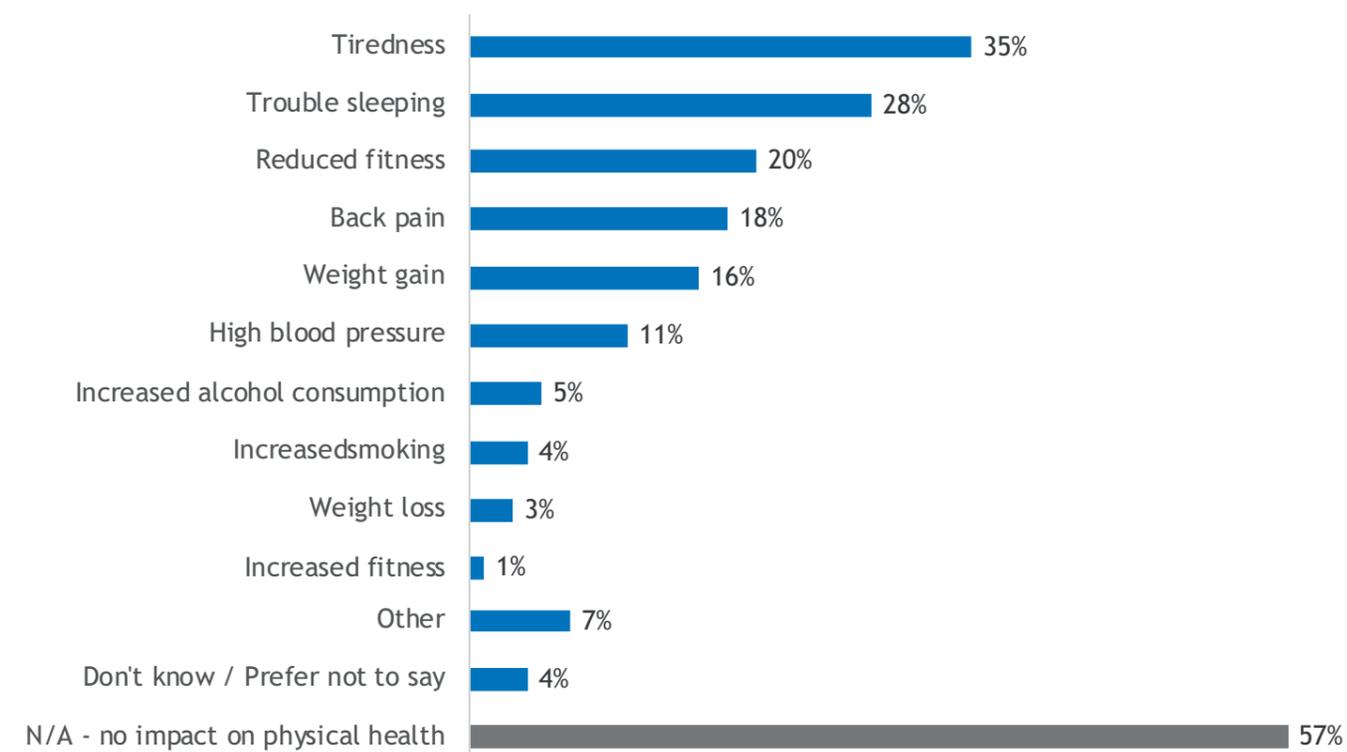
being mentioned as the most common impacts. Furthermore, some carers also highlighted that they are unable to take time out to take care of themselves if they become unwell, adding to the overall impact of caring on physical health.

*“I can't really afford to be ill, I just carry on as best I can.” – F, 62, cares for mother*

This percentage is lower amongst those who have been caring for less than a year (26%), and higher amongst those who have been caring for more than ten years (46%). Of those who began caring between a year to five years ago, over a third (36%) reported feeling a change in their physical health, and this trend continues into the overall time spent caring, as half (51%) of those who dedicate 30 or more hours per week to caring reported feeling physical effects upon their health.

This may derive from the fact that respondents were more likely to report feeling an impact upon their physical health as a result of caring for either their spouse (47%) or child (49%). In these cases, the carer is significantly more likely to be living with the person they are caring for; almost half of those who live in the same house reported feeling a decline in their physical health (43%), whilst this figure is lower for those who live separately from the person requiring care (33%). This also serves as evidence for the fact that additional hours spent caring tend to have a detrimental effect upon respondents' physical health, as carers are rarely 'off the clock'

**Figure 7: Impacts on physical health**



**Base: all unpaid carers (n=2,217)**

whilst living the same space as the person they are caring for.

Women were significantly more likely than men to mention an impact upon their physical health (42% vs. 36%). This is a result of women being more likely to report tiredness (38% vs. 31%), trouble sleeping (31% vs. 24%) and weight gain (19% vs. 13%).

Carers aged 50 and over were more likely than those aged 16-34 to report the majority of impacts on physical health. For example, 38% said that they felt tired as a result of caring, compared to 14% of carers aged 16-24. Generally speaking, back pain is more prominent amongst older age groups and this is heightened by being a carer, with around one in five (19%) carers aged 50 and over mentioning this compared to one in ten (11%) of younger carers aged 16-24. Older carers also spoke about experiencing increasing difficulty fulfilling their caring role over time, as a result of a decline in their own health due to age – for example, experiencing general wear and tear and feeling tired more quickly.

*“I’m not in great health myself, I’m now diabetic, and I have limitations to my walking abilities as well because of that...and my memory isn’t quite what it used to be...so each year it’s getting harder.” – F, 62, cares for spouse*

Back pain was a common symptom among those caring for people with physical disabilities (27%) or conditions such as COPD (26%) and long-term chronic illness (25%), likely due to the physical forms of care which need to be administered when the person requiring care needs to be helped out of bed, or bathed, for example. Back pain was also a heightened impact for carers who are limited a lot by a disability, with one in three (34%) having reported this compared to 11% of carers without a disability.

Weight gain, mentioned by one in six (16%) carers, was more common among carers of people with mental health conditions, with a quarter reporting this. Participants in the qualitative phase spoke about not having time to cook healthy meals, and using food as a source of comfort which, coupled with a lack of spare time available to dedicate to exercise, may also be at the root of the weight gain mentioned.

*“I tend to eat and eat and eat and eat again and again.” – F, 48, cares for child*

## The impact on education

Education / training is the area where caring is least likely to have had an impact, with just over one in ten (12%) carers having reported this.

The impact of education is most likely to be felt by younger carers – which is likely due to them being the traditional school age or slightly above this – with three in ten carers aged 16-34 saying that their education and training has been affected due to their caring role. In fact, for almost all of the impacts on education, younger carers were more likely to report them than their older counterparts. For example, 12% reported decreased performance at school / university or having no rest between school and college, whilst one in ten said they had to

stop education all together. These findings were reflected in the qualitative phase where young participants described having to complete homework late at night, negotiating extensions to school deadlines, retaking exams and deferring/delaying university education.

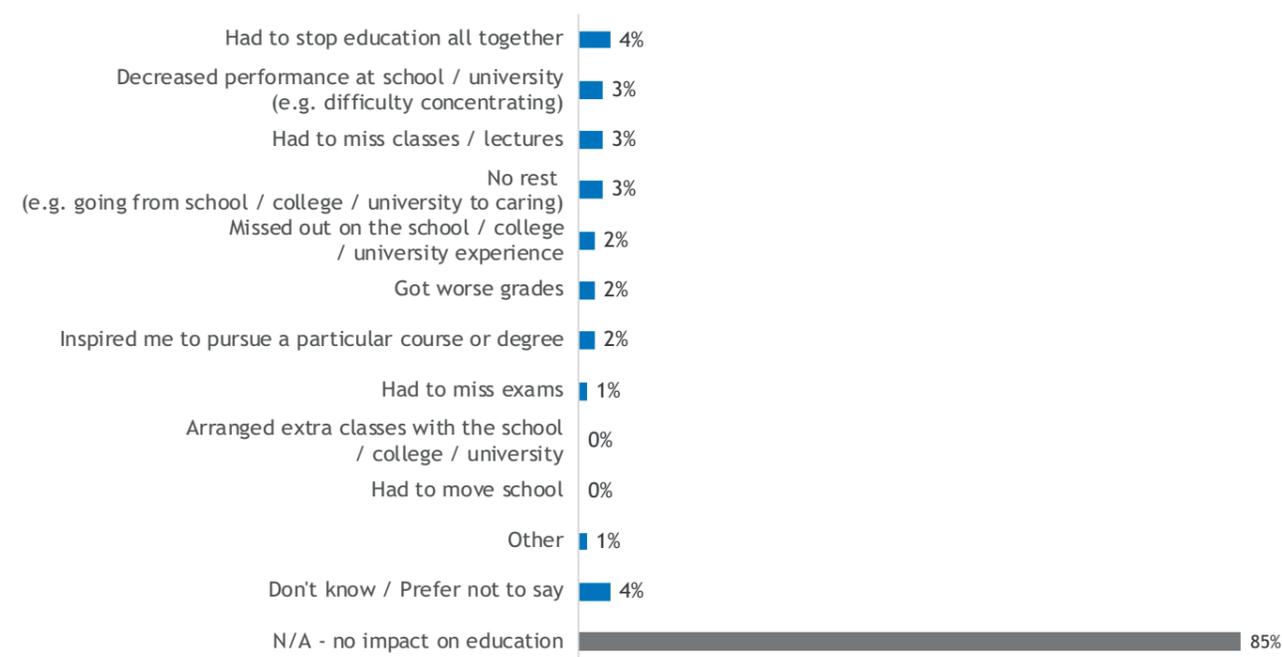
Some of the young people we spoke to also mentioned varying levels of awareness, understanding and support from education professionals in relation to their role as an unpaid carer and the potential impact of this. Where young carers were offered a supportive and flexible environment, it is evident that education can become an ‘escape’ for them and something to focus on.

*“I’m almost grateful that I had already started university because it meant I had something to keep going with.” – F, 24, cares for sister and grandmother*

Older carers were less likely to recognise the effect of caring on their education, with only one in ten (11%) of carers aged 35-64 mentioning this, falling to just 2% of carers and 65+.

In keeping with earlier findings, those who provide care for 30 or more hours per week were more likely than those caring for less than 30 hours to mention the impact on their education / training (18% vs. 7%). This is largely due to these carers being more likely to have had to stop education altogether (7% vs. 2%), which is likely due to having a lack of time for education due to the full time nature of their caring role. This ties in with a larger proportion of carers for their child saying their education / training has been affected (19%), as many of these carers will be dedicating longer hours to caring on a weekly basis.

Figure 8: Impact on education



Base: all unpaid carers (n=2,217)

**Aisha\* is 18 and is a carer for her father who has mental health problems**

She has been caring for her father for ‘as long as she can remember’. Aisha is currently re-sitting her A-Levels and is hoping to go to university to study medicine. She has received little support personally, and much of the support Aisha has been offered she describes as short-term and unsuited to her age group.

Aisha’s father requires emotional and practical support (e.g. help managing finances); her older relatives do not speak English fluently, so Aisha is left to take on the bulk of this support herself. Aisha says that she has tried to reduce her caring role as she has grown older, but feels guilty for this and worries about what will happen if she is not involved.

School was an escape when Aisha was younger, however, recently she has found it harder to keep up with school work; this was exacerbated last year when her father went into hospital. She found herself struggling to balance the emotional toll of supporting her father with her academic work, and sought help from her teachers; while they initially seemed understanding, they soon expected her to be completing her school work on time and were unable to provide any longer term support. She says she did not achieve the grades she wanted in her exams, and has concerns about the impact of this on opportunities for further study.

With the support of a teacher Aisha learned that she could retake, and submit information to universities for extenuating circumstances as a result of her caring role. However, it took her a month to gather the evidence she needed from the relevant agencies, and she still has concerns that universities will not take her situation seriously.

Aisha says that information about unpaid carers should be provided in schools from a young age; she thinks this would have helped her identify her carer status and access support a lot earlier than she did. She would be interested in any online/ telephone/face to face resources that provide emotional support, advice and reassurance for carers, as she still feels unsure she is doing ‘the right thing’.



*“They [teachers] were all sympathetic...for about two days. And then it became - ‘you haven’t given this work in to me, when am I going to get this’... ‘I know this is hard, but life is hard, so get over it’- It made it feel a lot worse, because I blamed myself more, I thought maybe I’m just not strong enough to handle this, maybe I’m being weak.”*

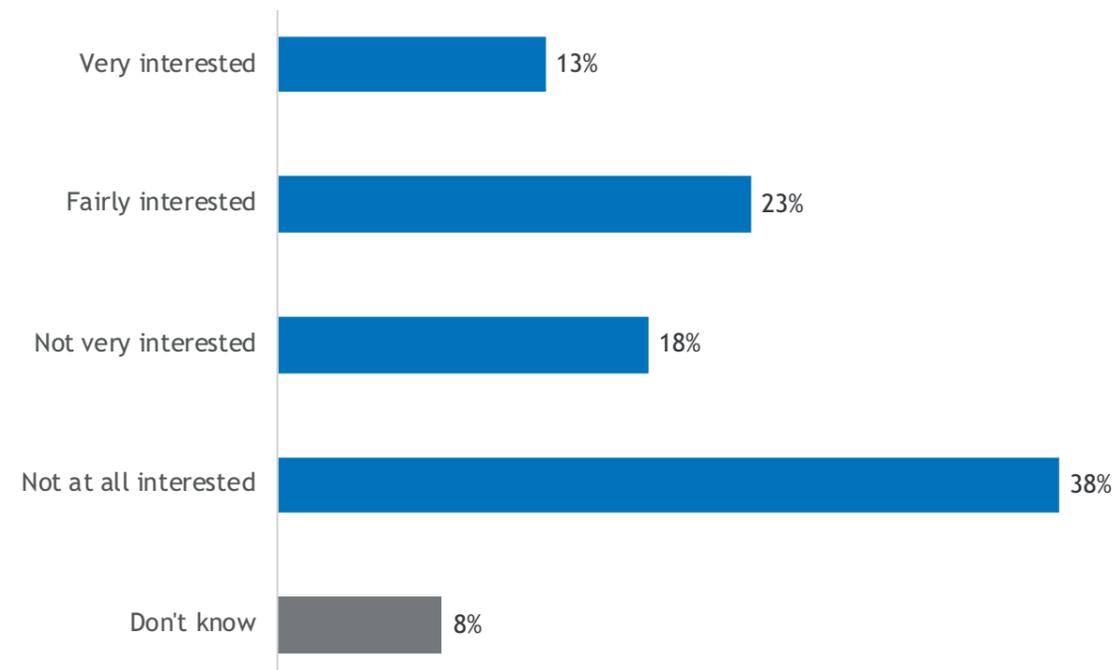
Carers of someone with autism were most likely to report an impact on their education / training (21%), followed by those caring for someone with a physical disability (19%), mental health condition or learning disability (both 18%).

Approximately a quarter (27%) of carers mentioned that there was at least one type of further / higher education that they would have liked to partake in but could not due to their caring responsibilities. It was most common for carers to feel like they had missed out on studying a degree (12%), followed by any other technical, professional or higher qualification (8%) or higher education below degree level (e.g. nursing / teaching qualification or university diploma) (5%). This was more pronounced among young carers, with one in five carers aged 16-34 saying that they would have liked to have done a degree. As with earlier findings, carers who dedicate 30 or more hours to caring per week were also more likely to report this (15%).

**Preferences for continuing higher education**

Overall, a third (36%) of carers reported that they are very or fairly interested in starting or continuing further/higher education

**Figure 9: Interest in starting or continuing further/higher education**



**Base: all unpaid carers (n=2,217)**

continuing further or higher education, though a larger proportion (57%) are not.

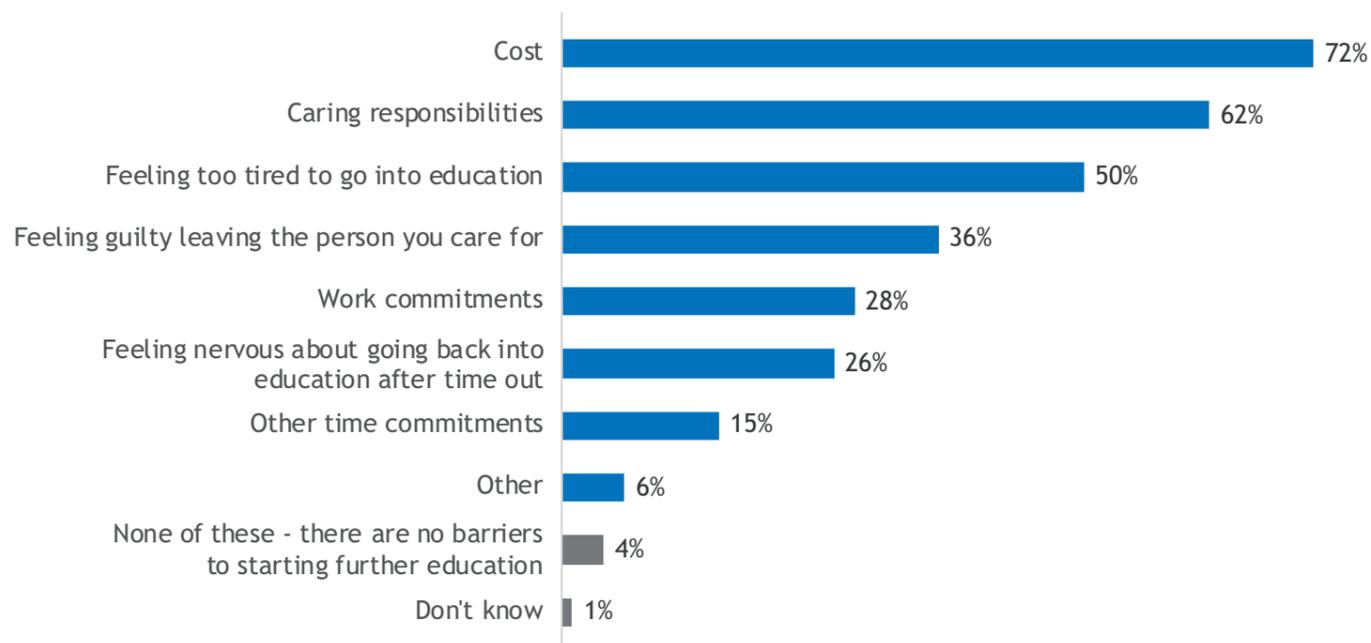
Younger carers were more likely to express an interest in starting or continuing further or higher education, with over half (55%) of carers aged 16-34 reporting this, in comparison to close to two in five (38%) of those aged 35-64 and 16% carers aged 65+.

Whilst a sizable proportion expressed an interest in education, there are a number of barriers to doing so. Amongst those interested, the cost of pursuing higher education was referenced by the majority (72%), whilst around three in five (62%) also reported that their caring

responsibilities were a deterrent in themselves. Half felt too tired to commit to education, and a further 36% felt guilty for leaving the person whom they care for, in order to pursue further educational achievements. Only 4% felt that there were no barriers at all, with this figure being even lower amongst those caring for people with particularly long-term or chronic illnesses (2%).

During the qualitative phase, one carer told us that she was trying to get back into the medical profession, which requires a multitude of exams and volunteering experience. She notes that the combined challenges of cost and time have meant that the process has been particularly long; she must save up to pay for each exam, find time to study, and must also secure childcare in order to gain volunteer experience.

**Figure 10: Barriers to starting/continuing further/higher education**

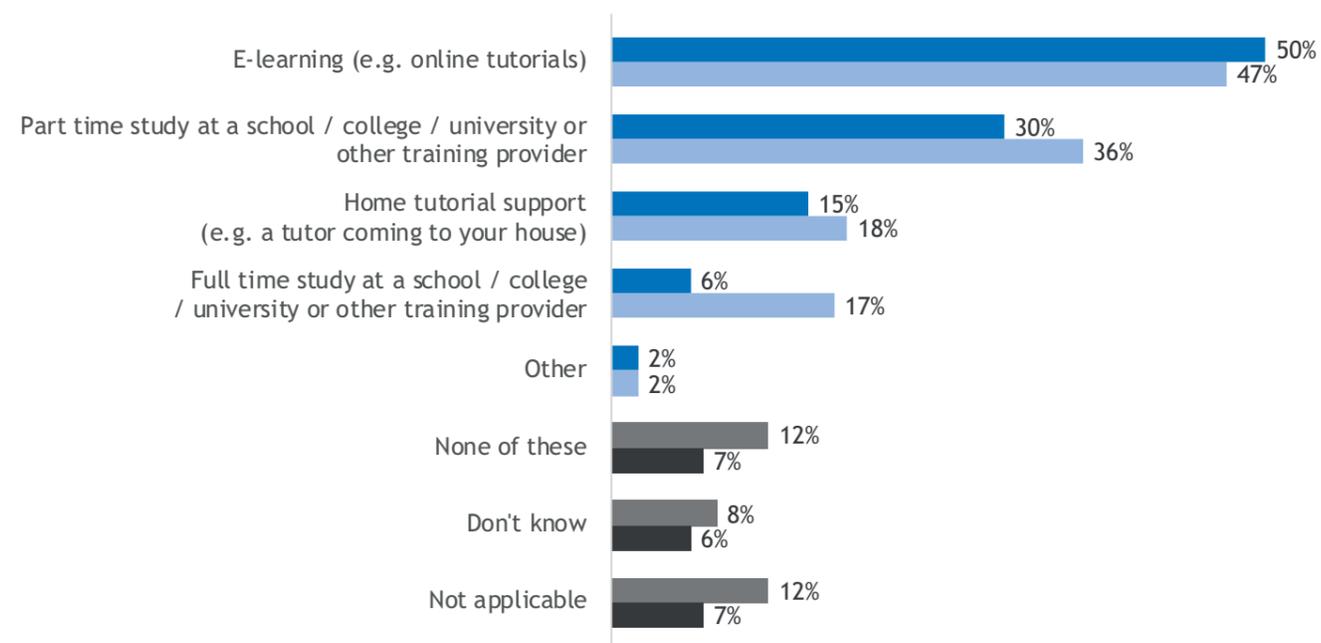


**Base:** those interesting in starting/continuing further/higher education (n=740)

*"It's taken a long time because all these exams cost money." – F, 48, cares for child*

Half of carers reported that e-learning in the form of online tutorials would be their preferred way of learning whilst continuing in their role as a carer, with studying part time being the option favoured by just under a third (30%) of respondents. Home tutorial support (15%) and full time

**Figure 11: Accessible ways of learning**



**Base:** all unpaid carers (n=2,217); all aged 16-34 (n=240)

study (6%) were less often mentioned as preferable ways of learning.

E-learning is a popular option for many carers, perhaps due to its accessibility, meaning that carers would be able to access online modules in their own time. This was a preferred option for carers regardless of time spent caring per week, though was slightly more popular among women (52% vs. 47% men), white carers (51% vs. 42% BAME) and carers aged 35-64 (54% vs. 47% of 16-34 and 40% of 65+).

*"Time is at premium and you are constantly exhausted. Access to suitable online content is critical." – M, 63, cares for spouse*

Part time study is the next most preferred means of learning, particularly for the youngest carers aged 16-24, with two in five citing this. This is also preferable for carers that devote less than 10 hours per week to caring (37%), most likely a result of them having more time available to dedicate to learning.

Full time study is most likely to appeal to younger carers, with 20% of those aged 16-24 saying that this would be preferable for them, 15% of 25-34 year olds, 5% of 35-49 year olds and just 3% of those aged 50 and over.

**Adenike\* is 48 and has been a carer for her son for the last 7 years.**

Adenike's son has been diagnosed with Global Developmental delay which impacts his behaviour and overall development. Adenike feels isolated through her role as a carer; she is unable to leave her son with others and feels she needs to watch him all the time.

Adenike receives 8 hours paid-for childcare per month through the local authority, however has so far been unsuccessful in securing someone who is willing to take care of her son. She says that his behaviour and additional needs mean many professionals prefer not to look after him – she says carers expect at least three hours of care booked at a time in order for the travel to be worthwhile, and feels the pay is not high enough to encourage experienced carers to apply. Adenike works 2 night shifts at the weekend when her son can be looked after by his father.

Adenike is a registered doctor in her birth country, however she has to gain registration with the General Medical Council in order to practice in the UK. This means she is currently studying for exams and trying to find time to volunteer in order to meet the GMC requirements; ideally she would like more time to pursue this, however she fits study in around her son's school hours. She says that it is taking her longer than she had hoped to gain the necessary qualifications, as she has to save up for each exam and the accompanying text books. She stresses that, when it comes to her own education, it takes a backseat to her son's needs.

Adenike's main challenge when accessing support is that she does not know what is available, so she would like a resource with lots of options. She would like to connect with other carers, and feels that this would help with the isolation she feels, however she does not know how to do this. She would also like more knowledge and education surrounding how to best toilet train her son and improve his speech and communication so that she can support his development at home. She thinks the best way to access extra support and training for carers is online, especially through videos, as this is the most flexible format; it is important for resources to be free, as her current education course is already expensive and finances at home are tight.



*"When you leave your child, you must be able to make a bit of money - if I go back to the medical profession...if I do that then at least I can afford to pay someone to look after my son."*

*"You might not know what you need until someone says 'you need this'. I would like to know what is available."*

## 5. Support and information

### Support

Around half (51%) of carers reported that they had received some kind of information or support to help with their role as a carer. Most commonly, carers had received access to equipment such as stair lifts or adaptations (17%) or information on the support available to carers (16%). Around one in ten mentioned getting the opportunity to meet other carers, employer support, emotional support, and financial advice or information.

Figure 12: Types of support received



Base: all unpaid carers (n=2,217)

Notably, close to half of carers reported that they had not received any support for their role as a carer (47%). This was most common among those providing lower amounts of care (51% among those providing under 10 hours per week), but even among those providing 30 hours or more per week, 43% said they had not received any form of support. Other groups that were more likely to report not having received support include:

- Male carers (50% compared with 44% of female carers)
- Middle aged and older carers (50% of those aged 35-64 and 45% of those aged 65+, compared with 36% of carers aged 16-34)
- Those not living in the same accommodation as the person they care for (50%)

- Those caring for a friend or neighbour (55%)

The age of the person cared for had a significant impact on the extent of support received by the carer. Those caring for someone aged up to 19 (where the reasons for care were mainly autism, other learning disabilities and mental health conditions) were more likely to have received various types of support, including an opportunity to meet other carers (22%), training on the specific condition/illness (16%), and advice on how to provide care (16%), compared with those caring for people in other age groups. Overall, 64% of this group had received some form of support; this proportion falls to 49% among those caring for someone aged 75 or older. The only area in which those caring for someone aged 75+ were more likely to receive support was equipment such as stair lifts and adaptations (received by 22% of this group, compared with just over one in ten among those caring for younger age groups).

Similarly, the reason for caring had an impact on the support received by the carer. Those caring due to autism or learning difficulties were most likely to have received some form of support (61% and 60% respectively); this broadly describes the same pattern outlined in the above paragraph, since those aged up to 19 were largely caring due to these conditions. However, those caring due to dementia were also somewhat more likely than other groups to have received support (57%).

Overall, the most common source of support was social services or the local authority: 15% of all carers mentioned receiving support from this source. Around one in ten reported having received support from a charity or voluntary group (11%), family or friends, or a professional healthcare worker (both 10%). Other sources of support, such as a local carers centre, were mentioned by less than one in ten carers.

The majority of carers (74%) felt that some form of support, or additional support, would be useful to them (this includes both cases where they were had not received support but wanted to, and those where they had received some support but wanted further support). Most commonly, carers expressed a desire for emotional support (33%). Around a quarter felt that information and advice on the support available to carers (26%), respite care (23%) and financial advice and information (22%) would be useful to them.

Figure 13: Types of (further) support that would be useful to carers



Base: all unpaid carers (n=2,217)

Generally, it was those in the middle age years that were most likely to want additional support, in comparison to both younger and older carers. For example, 38% of carers aged 35-49 said that emotional support would be useful, compared with 34% of carers aged 16-34, 31% of 50-64s and just 27% of those aged 65+. A similar pattern can be seen in relation to financial advice and information, and out-of-hours provision. This may reflect the greater pressures faced by those in the middle age years, who may often have dependent children in addition to caring responsibilities. Overall, just 11% of carers aged 35-49 stated that no type of additional support would be useful to them, which rises to 17% among 50-64s and 22% among those aged 65+.

Carers aged 16-34 were somewhat ambivalent or uncertain about their support needs: while only 9% stated that they would not find additional support useful, 14% said they did not know; a higher proportion than seen in any other age group.

As might be expected, carers providing greater amounts of care were more likely to think additional support would be useful to them. Those providing 30 hours or more per week were significantly more likely than those providing fewer hours to mention various types of support, including emotional support, respite care, financial advice/information and help with household tasks. However even among the lowest category (under 10 hours per week), 70% mentioned one or more type of support that would be useful to them (this compares with 77% among those providing 10-29 or 30+ hours of care per week).

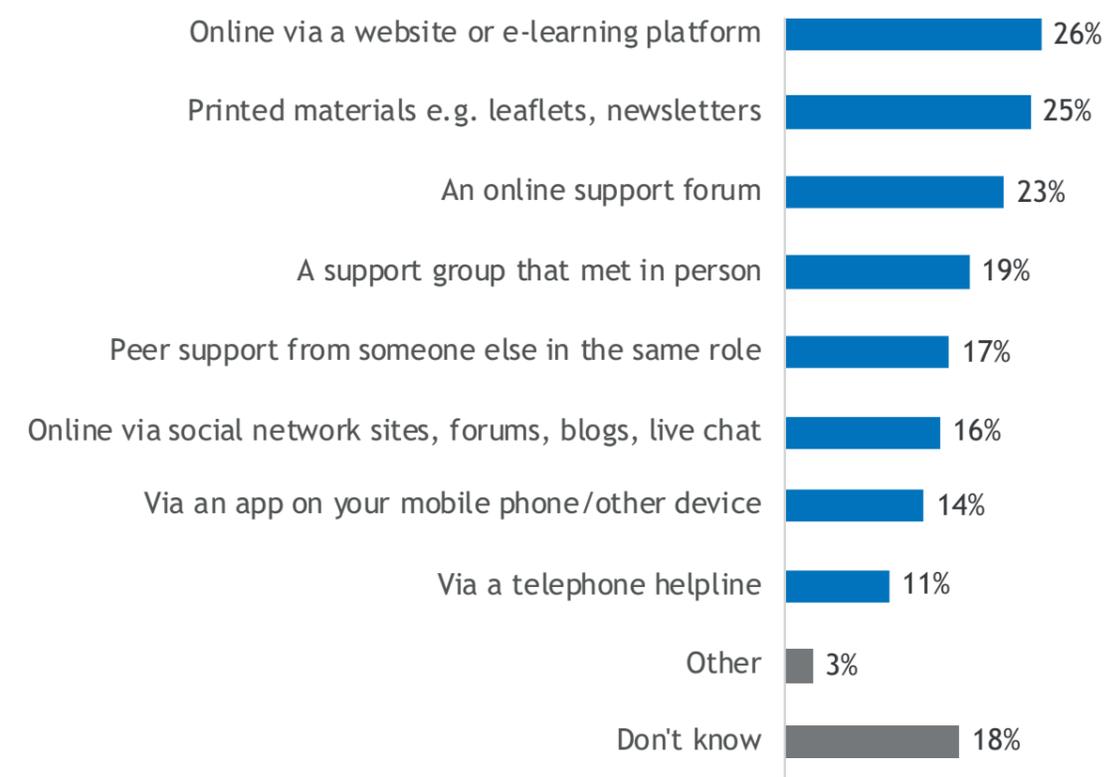
**Table 1: Types of (further) support that would be useful to carers – by age of carer**

	16-34	35-49	50-64	65+
Emotional support	34%	38%	31%	27%
Information and advice on the support available to carers	18%	31%	27%	25%
Respite care	18%	24%	25%	22%
Financial advice and information	19%	29%	23%	16%
Help with household tasks	17%	21%	20%	22%
Help with transport	19%	21%	18%	14%
Training on understanding specific condition / illness	16%	19%	17%	12%
Access to equipment (e.g. stair lifts, adapted furniture, grab rails)	10%	18%	15%	15%
Advice on how to provide care	13%	17%	15%	13%
Someone to help understand/ manage professionals and organisations	13%	19%	15%	9%
Support from your employer (e.g. flexible working)	16%	20%	11%	1%
An opportunity to meet other carers	12%	15%	11%	11%
Training on how to provide care	12%	14%	12%	9%
Out of hours provision	7%	15%	11%	10%
Something else	2%	4%	5%	2%
None of these	9%	11%	17%	22%
Don't know	14%	12%	10%	8%

As discussed earlier in this chapter, those caring for younger people were more likely to have already received support for their role as a carer, compared with those caring for people in older age groups. Despite this, those caring for younger people were also the group most likely to want additional support: 80% of those caring for someone aged up to 34 mentioned one or more types of support that would be useful to them, compared with 76% of those caring for someone aged 35-54, and 72% of those caring for someone aged 55 or older.

When asked how they would like to receive these types of support, the most popular way by some margin was face-to-face with a support worker or trainer (44% of those wanting additional support). Around a quarter of this group mentioned receiving support online via a website or e-learning platform (26%), printed materials (25%) and an online support forum (23%). Collectively, 42% of those wanting further support mentioned an online channel (a website/ platform, a forum, or via social networks, blogs or live chat).

**Figure 14: How carers would like to receive support**



**Base: all wanting further support (n=1,644)**

Preferred channels for receiving support depended on the age of the carer. Those aged 16-34 were more likely than other groups to mention receiving support via an app (27%, compared with 14% of 35-64s and just 5% of those aged 65+). By contrast, those aged 35-64 had a stronger preference than others for support received via a website (30%, compared with 22% of 16-34s and 19% of those aged 65+), while the oldest age group were more likely than others to prefer face-to-face support. Despite these variations between groups, it should be noted that face-to-face support with a support worker remains the most popular option among all age groups (37% of 16-34s, 44% of 35-64 and 49% of carers aged 65+).

The qualitative interviews bear out the high percentage of carers who had not received any support at all – and many who had been in receipt of support only received it infrequently, piecemeal, or as a one off. This was attributed to a couple of reasons, one was that carers often simply had no idea of who to turn to for support – they often felt that, should they be entitled to help or support, it would have been provided, or at least signposted to them, by a medical professional.

Allied to this, they reported great difficulties in navigating the system – knowing who to turn to, at what point in their journey, and what they might be eligible to receive. Many feel that information about what support is available to them is scattered, and they would like to be able to see services available all in one place – currently, the system is incredibly difficult to navigate and get to grips with, and spread across the NHS and local authority provision. On top of which there seems to be a large amount of regional disparity – some areas have better provision than others.

*“There’s a lack of information out there - for example if I had an enquiry about what benefits she could be entitled to, or how does one make enquiries about what care packages are on the table. Just information and a clearer sense of structure of the whole care system - hierarchies and who to contact would have been useful. As well as power of attorney and understanding mental capacity etc.” – M, 42, cares for mother*

Much of this therefore fell into the category of ‘unknown unknowns’ – participants were as unsure of the landscape of care support as they were about what entitlement they might be allowed – this therefore makes it doubly difficult to provide targeted support to unpaid carers.

But as much as a lack of knowledge was a barrier, the qualitative interviews demonstrate that a lack of willingness to reach out and accept support is just as big a factor. This can be attributed to three main reasons:

- Perceptions of statutory-supplied care are negative and can often put people off – either from their own bad experiences, or, just as significantly, things that they have seen in the media. This means that participants often do not want to entrust the care of a loved one to someone who will provide a rushed, or perfunctory service.
- Tied in with the above, many feel that they know the people they care for well and understand their needs better than anyone – they need to trust that an external carer would be able to meet their needs in the same way, otherwise they would be too worried to hand over care and would be unable to switch-off from their responsibilities. For some there were cultural and linguistic considerations along with issues relating to pride and dignity.
- Third, and closely related to the others, was a sense of independence – those in receipt of care would rather try to manage independently for as long as they possibly can, and if they cannot manage, at least keep the provision of care in the family if at all possible.

*“I also have the added issue of my dad being a very proud man who insists that family look after each other and not anyone else. This is great in theory but not always practical in this day and age.” – F, 44, cares for mother*

## Case study - Simon

### Simon\* is 53 and has supported his wife for the last six years and cared for her for the last two years.

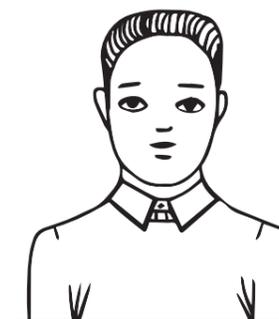
Simon’s wife was diagnosed with MS two years ago and had previously suffered with a tumour on her ankle, impacting her mobility and energy levels.

Simon’s wife’s condition ‘ebbs and flows’, so he left his job in order to care for her full time; he would have preferred to stay at work, however he felt the strain of working at night and caring during the day was too difficult. His role as a carer includes helping his wife move about the house, helping with cooking and cleaning and helping her to wash/bathe.

Simon and his wife receive a range of financial help including housing and council tax benefits, PIP, carer’s allowance, as well as his military pension. They have been successful in accessing help from the housing association following a visit from an occupational therapist. In order to support his wife, they had central heating and double glazing installed, as well as a new shower and handrails around the house to improve accessibility. Simon is satisfied with the support he has received and thinks the process was simple, but he believes the support available to carers should be better signposted; he has only recently found out that he is able to call the hospital and ask for help with his wife’s condition.

Simon is very distrustful of the local council and says he would never try to access help through them, thinking they would resent giving help as much as he would resent asking for it. He also does not think they would be able to provide much help by way of care due to funding cuts and so would prefer to access help through organisations like the British Legion and the RAF Association in the future, if needed. He finds the future difficult to think about, so their long-term support needs tend to go unspoken about.

Simon does not think he requires extra training to help with his caring role per se; he already goes online to look for help and support and spends a lot of time researching his wife’s condition to educate himself. However, Simon struggles with the emotional strain of caring and does not know where to access professional support for himself; he feels he has a duty to his wife to care for her but is sometimes scared by his role and what the future holds. His wife is very proud and does not like people knowing about her condition, meaning Simon has limited people to turn to in his own social circle.



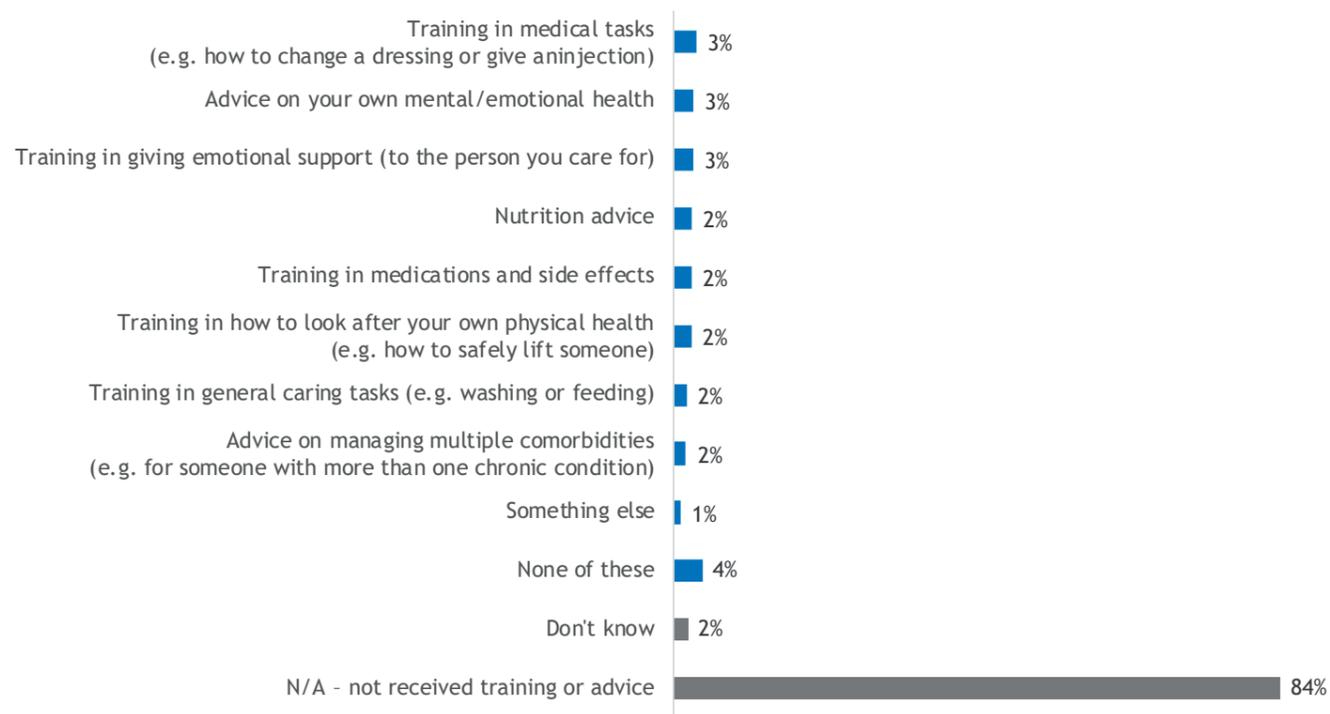
*“When the time comes it will be hard for both of us, my wife admitting she needs help and me admitting I need help. They’re both going to be difficult decisions to make”*

*“I’m frightened that as time goes by it will become too difficult for me”*

## Training

Overall, 13% of carers reported having received some form of advice or training in relation to their role as a carer (i.e. advice on how to provide care; training on how to provide care, or training to understand the specific condition or illness). These respondents were asked a more detailed question on the training or advice they had received. Most commonly, carers had received training in medical tasks, advice on their own mental/emotional health, and training in giving emotional support to the person cared for (3% of all carers, in each case). Most other specific types of training/advice listed had been received by two percent of all carers.

Figure 15: Types of training/advice received



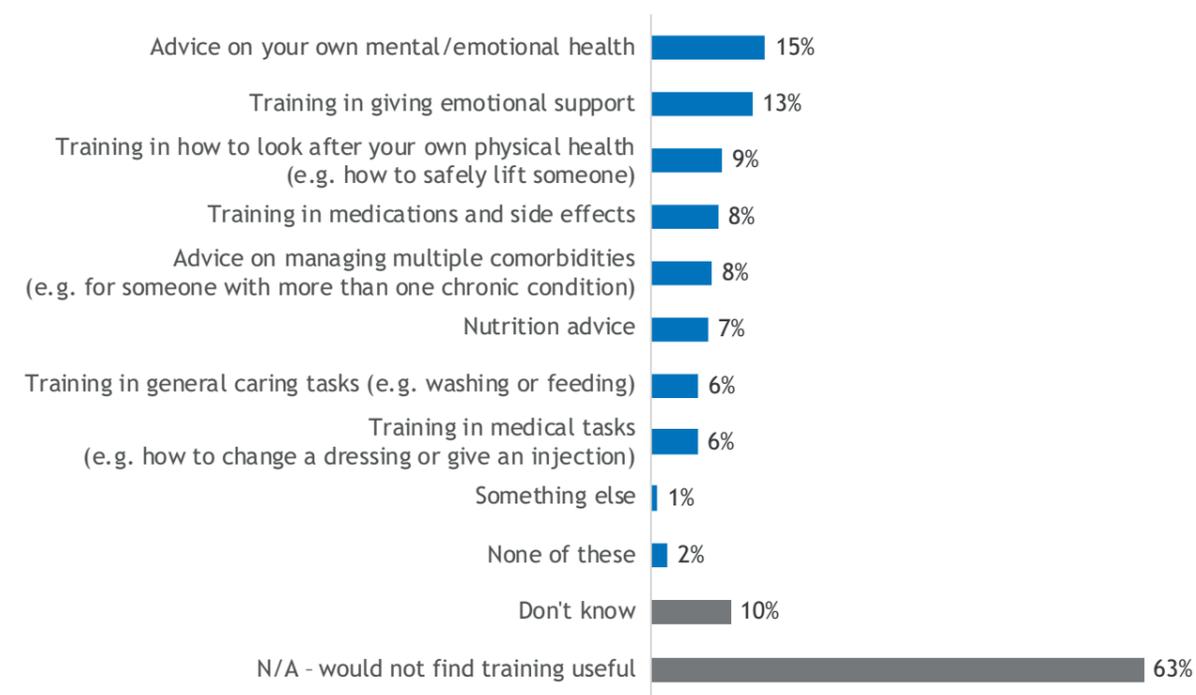
Base: all unpaid carers (n=2,217)

Those caring for someone aged up to 19 were more likely to have received various types of training, including training in medical tasks (8%), giving emotional support to the person cared for (7%) and nutrition advice (6%). These proportions fall to 1%, 2% and 2% respectively among those caring for someone aged 75+.

Interestingly, those providing 30 hours or more of care per week were not notably more likely to have received training than those caring for fewer hours. The only exception to this was training in giving emotional support to the person cared for, which 4% of those caring for 30 or more hours per week had received, compared with 2% of those caring for under 30 hours.

Reflecting the low proportion of carers that reported having already received specific training or advice in relation to caring, a larger proportion (27%) indicated that some form of advice or training (i.e. advice on how to provide care; training on how to provide care, or training to understand the specific condition or illness) would be useful.

Figure 16: Types of training/advice that carers would find useful



Base: all unpaid carers (n=2,217)

Continuing a broad pattern seen earlier in this chapter, younger carers and those in the middle age years were more likely to state that training or advice on how to provide care would be useful to them, compared with carers aged 65+. For example, 10% of carers aged 16-34, and 8% of those aged 35-64, mentioned that nutritional advice would be useful to them, compared with 4% of carers aged 65+. Advice on their own mental/emotional health was a particular priority for those aged 35-64: 16% of this group stated that such advice would be useful, compared with 12% of 16-34s and 11% of carers aged 65+. There was no area where carers aged 65+ expressed a greater appetite for training/advice than younger carers.

As might be expected, those providing more hours of care were more likely to feel that training or advice on how to provide care would be useful to them. For example, 10% of carers providing under 10 hours of care reported that training in giving emotional support to the person cared for would be useful, rising to 14% of those providing 10-29 hours, and 15% of those providing 30 hours or more. Similarly, 11% of those caring for under 10 hours indicated that advice on their own emotional or mental health would be useful, rising to 16% of those providing 10-29 hours, and 17% of those providing 30 hours or more. It is interesting that there is no significant difference in these views between those providing 10-29 hours and 30+ hours, suggesting that the main impacts or challenges of providing care take effect before the point of 30 hours per week.

The qualitative interviews shone a strong light on the emotional impact of providing informal care, and the often unexpected levels of stress, isolation and despondency that this can lead to. The fact that advice on mental and emotional health is the most sought after training is not surprising – few mentioned the need to receive training on the physical aspects of providing

care, rather it was the need for emotional support that was mentioned. As the quantitative data shows, this is twofold – both the need for the carer to receive emotional support as well as to provide it for the person they are caring for.

As much as emotional support is important, it was also the need for understanding – to be able to talk to other people in similar situations in an empathetic environment, and, as much as this was important, it was also the companionship that this brings. Some of this can be replicated, to a large extent, in an online setting (and ideal for those who are unable to leave the house due to the care that they provide – for example mothers caring for children with autism) but the benefits of local face to face support groups were a theme across all the interviews. For so many this is about reassurance – their need to know they are doing things correctly, especially when dealing with any sort of deterioration in health. Participants talked about the combination of self-learning and common sense that has taken them to this point, but the ability to ‘sense-check’ what they are doing would be valued.

*“I am present on the facebook networks and some of them do a great job and some of them are terrible. Networking only works if you have people with similar levels of engagement - also it's very easy to set up a 'scare board'. Supporting only works if you are not frightening each other. Support networks are very good but only when they are run as a program. When you had a diagnosis you used to be offered a course where you went to learn with others. Maybe something performed online in an open session. It doesn't have to be a first time learning experience.”*

**– F, 38, cares for children**

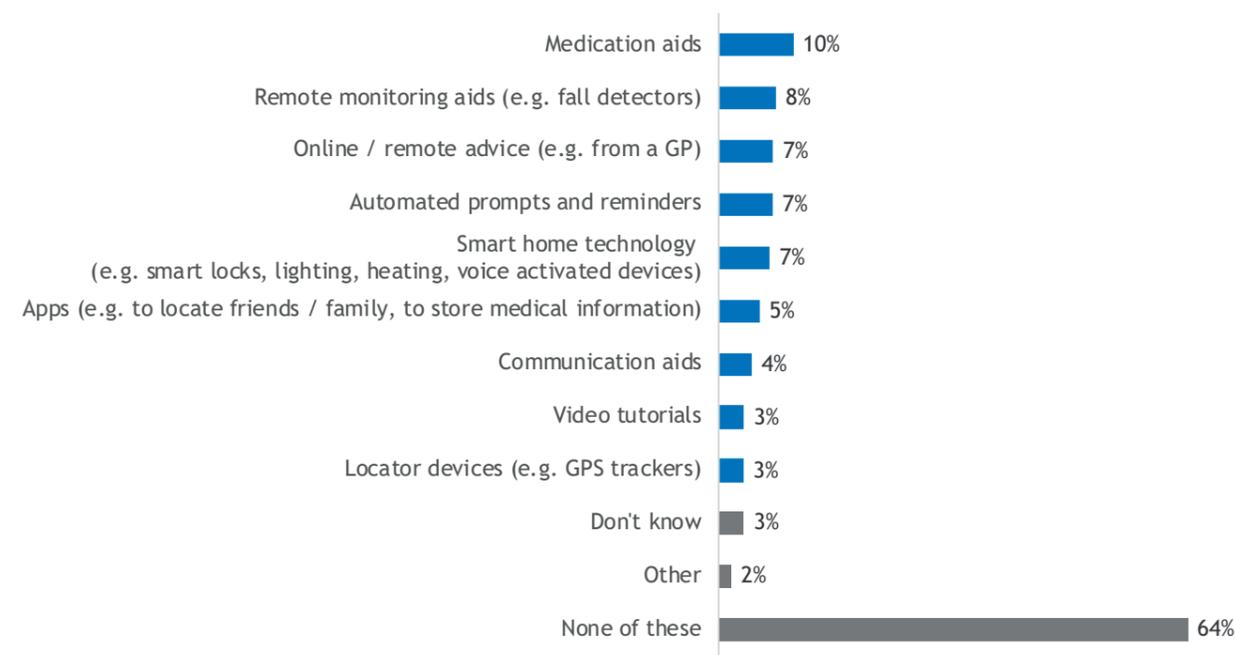
In terms of the format of this training, flexibility was the watchword, participants talked about how they want to be able to dip in and out of the training as allowed by their caring needs. As such, online portals and modules may work well here – and this is a familiar format to some we spoke to who were studying this way through the Open University.

## Technology

There is a growing world of technology that aims to make the caring role easier. Yet whilst one in three (33%) carers reported that they have used one or more of the types of technology listed, that means a further two in three carers have not, which perhaps seems low considering the technological environment that we live in.

Carers were most familiar with medication aids, with one in ten saying they have used them to assist with their role as a carer. Following this, remote monitoring aids (8%) and online / remote advice, automated prompts and reminders and smart home technology (all 7%) are the next most commonly used types of technology.

**Figure 17: Types of technology used to assist with the caring roles**



**Base: all unpaid carers (n=2,217)**

Young people are often the earliest adopters of new technology, a finding which is mirrored in the results. Carers aged 16-34 were more likely than those aged 65+ to say they have used smart home technology, such as smart locks, lighting, heating, voice activated devices (17% vs. 5%), automated prompts and reminders (13% vs. 5%), online remote advice (12% vs. 6%) and apps (11% vs. 3%), amongst other technologies.

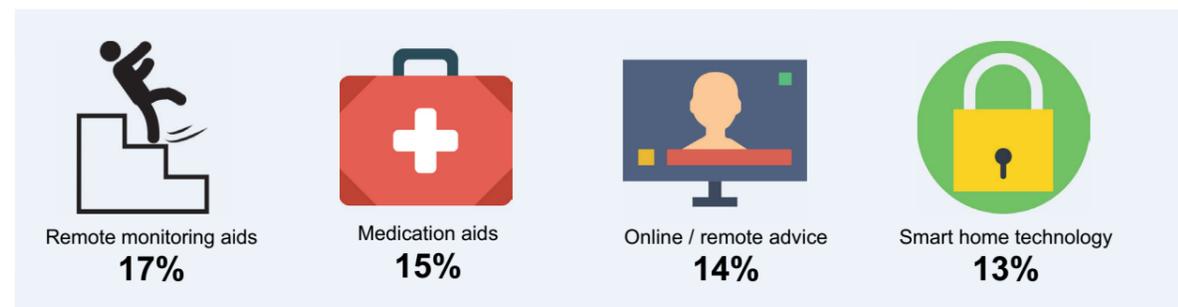
Men were more likely than women to report having used smart home technology (10% vs. 5%) and automated prompt and reminders (9% vs. 6%).

Remote monitoring aids, such as fall detectors, can detect when someone has taken a fall and notify the person caring for them, which can be useful if someone is living independently. A result of this, carers that do not live in the same home as the person they care for were more likely to mention using these (14% vs. 5% of those that live with the person they care for). Carers of people aged 75 and over (13%) were also more likely than average to report using this type of technology. By contrast, carers that do not live with the person they live for were more likely to say they have smart home technology (8% vs. 5%) and automated prompts and reminders (8% vs. 6%).

Recent carers were more likely to use technology to help them with their role, perhaps suggesting that new technologies are starting to be more widely adopted (it should also be noted that there is a correlation between age and time spent caring, with younger carers tending to be more recent carers). Two thirds (68%) of carers that have been providing care for 5 or more years reported not having used any of the types of technology, compared to 46% of those who have been caring for less than a year.

Among carers that reported having used technology to assist with their caring role, remote monitoring aids came out as the most useful (17%), followed by medication aids (15%), online or remote advice (13%) and smart home technology (13%).

**Figure 18: Most useful types of technology used to assist with the caring role**



Men were more likely than women to say that smart home technology (18% vs. 8%) and video tutorials (7% vs. 4%) were the most useful, whilst women were more likely to favour online / remote advice (16% vs. 10%).

Younger carers aged 16-34 were most likely to cite smart home technology as the most useful, with one in five (21%) doing so, compared with 10% of carers aged 35-64 and 13% of carers aged 65+. Contrastingly, older carers aged 65+ were more likely to see the value of remote monitoring aids, with a fifth (21%) saying that these are the most useful type of technology compared to 9% of carers aged 16-34.

In line with earlier findings, carers that do not live in the same home as the person they care for were more likely to mention remote monitoring aids as the most useful type of technology (33% vs. 8% of those that live in the same home).

In the qualitative interviews the subject of technology was not often raised spontaneously, matching the 64% in the survey who stated they do not use any technology in their caring role. For most, should the need arise for technology to be used, then by this time they feel they would have crossed over into formal, professional care. That said, some did have an appetite for small home improvements to allow them to live their lives in more comfort.

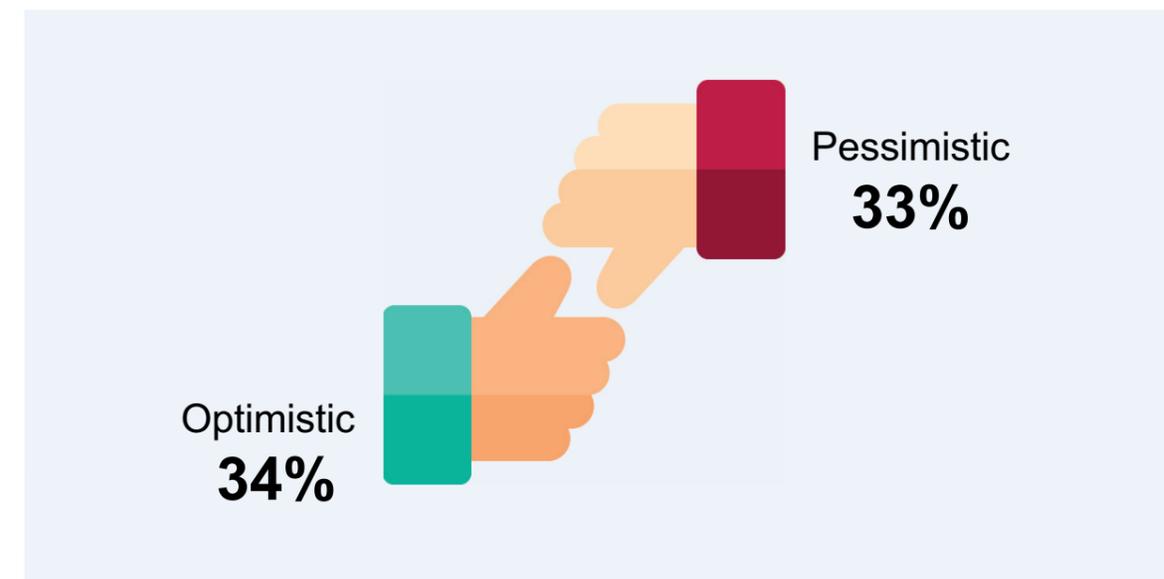
*"I have given my mum big button phone with SOS button to press, so mum knows when in need of help to press that, and I get message saying help." – F, 52, cares for mother*

*"A remote control to control her lights, so that she doesn't have to get up...that would make things easier for her." – M, 25, cares for grandmother*

## 6. Future outlook

Opinions on carers' future outlook are evenly split, with a third saying they are optimistic (34%) whilst the same proportion feel pessimistic (33%), or neither of the two (31%).

**Figure 19: Whether future outlook is optimistic or pessimistic**



There is a correlation between time spent caring and optimism, with those providing care for less than 10 hours a week feeling most optimistic about their future (44%), in comparison to those caring for 10-29 hours (35%) and 30 or more hours (26%). This ties in with carers who live with the person they care for.

Carers that look after a sibling were most likely to feel optimistic, with close to half (47%) reporting this, higher than for carers of a spouse / partner (32%) or a child (29%).

Of the carers we spoke to in the qualitative phase, who were providing a high level of care on a regular basis, many expressed concern over what the future would look like for them and the person they care for, and were aware to an extent of the impact of providing care long-term. In terms of the support available to them, many of the carers we spoke to felt that their situation would not change. However, it was not uncommon for respondents to say that they do not tend to think about the future, preferring to take each day as it comes.

*"Further down the line I'm sure I'll be quietly sitting there and having a little sob and wondering how I'm going to do this next time after I've found my wife on the floor." – M, 53, cares for wife*

*"I doubt it (the system) is going to change. If it's going to change it will probably be worse" – F, 23, cares for parents*

## 7. Conclusions

This research clearly shows that the story of unpaid carers is complex, and is one that needs to be heard as widely as possible. Many unpaid carers are simply doing their best in difficult situations, caring for family members for as long as possible to avoid the need for care by unfamiliar people, in possibly unfamiliar settings. The continuity and familiarity of their continued presence, while challenging for them, is seen to ease the burden on their loved ones at times of emotional upheaval and future uncertainty.

This dutiful contribution, however, does not come without consequence. Many unpaid carers suffer for the service they provide, and often suffer in silence. Their social life is largely diminished, with close to two thirds (64%) of carers reporting an impact on their social life, a likely result of them spending much of their time indoors with the person that they are caring for. This isolation is often suffocating, and a cause of much mental anguish for those providing care – the lack of an outlet means that many emotions remain unreleased, and leaves many unpaid carers feeling uncared for themselves. In fact, half (49%) of carers said their mental health had been impacted due to their caring responsibilities, with over two in five (42%) reporting increased stress.

There is also the issue of preparedness for the future – a majority of unpaid carers we spoke to are simply treading water, and ‘keeping calm and carrying on’. Thinking about the future divides carers’ opinions, with a third feeling optimistic (34%), and the same proportion pessimistic (33%). Many have not put great thought into transitioning the person that they care for into more formal, professional, longer-term care, preferring instead to take each day as it comes. There were a couple of reasons for this – firstly they are ‘working’ in isolation, without anyone available to help them through the process or educate them about what is available, and, secondly, having conversations and planning for the future is difficult, both for them and for the person they care for. Trust also has a part to play here – many of those providing unpaid care are relatives of the person being cared for; they feel they understand their loved one’s needs better than anyone, and believe that professional care may not meet their current standards.

In terms of the needs of unpaid carers, it is worth remembering that the circumstances of their care are diverse and varied. Some provide care to loved ones with mental health conditions (21%), whereas for others there is a need to provide personal or physical care. Often, the care needs being met fall into multiple categories. Therefore, no two carers are alike in terms of their circumstances and needs.

One thing that does unite them however is a sense of isolation. The life of a carer is lonely, and they are often housebound - they have limited interaction with their peers, or those who could empathise with their situation, so there is a clear unmet need for local networks. The local aspect of such networks is valued, both because this will allow them to meet other carers in a face to face setting should circumstances allow, but also because services are often unevenly distributed across the country, so by keeping the points of reference local they can be more sure what they are able to access and benefit from.

There was less of an appetite for training as part of the caring role with a quarter (27%) of carers feeling this would be useful. Many feel that they have a good understanding of the emotional and physical needs of the person they care for already; however, some say it is reassurance they require, more than knowledge itself. There was some appetite for training with a more clinical

focus – helping carers to understand the pathology and progression of mental and physical health conditions, and speaking to others who are at different points along the journey of caring for someone in a similar way to themselves, to learn from, and educate in equal measure. Furthermore, there was some expression of interest in training and support around the emotional and coping side of providing care – both in terms of managing the emotions of the person being cared for (13%), but also in terms of carers’ self-care (15%); for many, the emotional strain of caring has the greatest impact on their life overall, and their emotional resilience is key to continuing their caring role.

Ultimately, the key themes here are a lack of time coupled with emotional strain, lack of flexibility to learn and train, feeding into social isolation and financial difficulty. It is therefore important to bear in mind that any education or training resource should account for these challenges as much as possible. Online is generally accepted as the most accessible, flexible route to information and resources, for studying for formal qualifications and interactive elements within this, such as opportunities to peer network, or an option to receive tailored, specialist advice, would address the issues of reassurance and social interaction.

## 8. Future Care Capital’s Recommendations

There is evidence in this report of concern amongst unpaid carers that their responsibilities are becoming increasingly difficult to manage. What is also striking is the difference in opinion about their future outlook - pessimism grows with the number of hours unpaid carers devote to caring each week. A key theme of this report is that unpaid carers feel forgotten whereas we believe they should feel they are a key part of their local community. We have a responsibility to recognise the contribution of unpaid carers and our recommendations offer a way forward with that in mind:

### 1. Convene a Carers Coalition: Identification, Signposting and Targeting of Information

Government should engage experts from all sectors to develop a new nationwide capability to help identify, invite consent from, then, signpost and target useful information in respect of unpaid carers. This would involve a coalition of public, private and third sector bodies acting in concert to ensure that useful and broad-ranging information; for example, financial advice, signposting to local support groups and help navigating the benefits system, is made available to the right people as and when required.

### 2. Establish a Flexible Education Taskforce for Young Carers

A dedicated Taskforce should be established to explore the potential to introduce flexible and/or online educational provision to improve the life chances of young carers. Its members would need to review legal provisions concerning school attendance and potential issues with off-rolling in the first instance, but could also invite experts to make recommendations about the scope to make use of digital technology in this regard. Crucially, the Taskforce would need to ensure that any such provision would not serve to further isolate potential beneficiaries.

### 3. Training and Support

The Government's adult social care Green Paper should include considerations around supporting carers' work-life-care balance - helping carers to manage their work commitments whilst maintaining their caring responsibilities, as well as preventing them from falling behind from the point of view of career progression. The Department for Work and Pensions, acting with Further Education providers at a local level, could also offer new training pathways for unpaid carers to help them re-enter the labour market if or when their caring responsibilities are reduced.

### 4. Tackling Hidden Costs

The Government could establish a Department for Work and Pensions (DWP) fund to support carers transport costs. A per annum transport payment or top-up could be allocated to help carers budget over a longer period of time and help reduce the administrative burden of managing such support. This financial assistance would be in addition to Carer's Allowance. The carers we engaged with in the course of undertaking our research identified that travel to and from medical appointments is making their tight budgets even more stretched.

### 5. Enhance the Rights of Unpaid Carers

The Government should look at new ways to prioritise the physical and mental health needs of unpaid carers. This might include committing to priority treatment for the most common mental and physical health issues developed in the course of undertaking a caring role. This recommendation could be included in the adult social care Green Paper to complement the Carers Action Plan's drive towards personalisation of health and social care services. Early intervention may help to mitigate some of the issues identified in this report around depression, tiredness and back pain.

## Appendix A – Breakdown of responses

Age	Percentage	Count
16-24	4%	98
25-34	6%	142
35-49	25%	562
50-64	39%	864
65+	25%	551

Gender	Percentage	Count
Male	39%	854
Female	61%	1363

Time spent caring (weekly)	Percentage	Count
Under 10 hours	28%	610
10-29 hours	27%	101
30 hours or more	41%	907

Person cared for	Percentage	Count
Spouse / Partner	35%	773
Child	18%	400
Sibling	3%	65
Parent / Parent in law	35%	786
Friend / Neighbour	3%	66

Condition (reason for care)	Percentage	Count
Dementia / Alzheimer's	14%	303
Cancer	6%	129
COPD	7%	155
Arthritis	25%	560
Heart condition	14%	317
Other long-term / chronic illness	24%	537
Mental health condition (e.g. depression, anxiety, bi-polar)	21%	467
Addiction (e.g. alcohol, drug)	2%	47
End of life care	2%	50
Learning disability	8%	186
Physical disability (e.g. cerebral palsy, muscular dystrophy)	12%	262
Other disability	18%	399
Other, please specify	14%	317
Autism	11%	240
Stroke	6%	141
Blindness / partial sight	8%	182
Paralysis / partial paralysis	2%	38

## Appendix B – Age summary

### Young carers

Young carers aged 16-24 were least likely to report an impact on their social life (49%), though this is still a sizable proportion. They were also less likely to say that their family life had been affected by their caring role, with only one in four (25%) mentioning this, which could be a result of them not knowing their family life any differently. As young carers are more likely to care for a parent, the impact of this on their family situation will likely manifest itself in different ways as opposed to older carers who might be providing help and support for children or their partner / spouse. This age group is also least likely to report an impact on their financial situation (24%) and physical health (18%). Young carers are less likely to have had to stop working all together, probably due to them being less likely to be in full time employment.

By contrast, young carers were most likely to say their education or training had been affected, a result of their life stage. Thirty-percent of carers aged 16-34 reported this, rising to over a third (36%) of carers aged 16-24. Carers aged 16-34 were more likely than their older counterparts to say that they would have liked to have done a degree but were unable to as a result of their caring responsibilities. The youngest carers aged 16-24 were most likely to feel report not being able to do GCSEs or equivalent (11%), AS/A levels (8%) or higher education below degree level (13%). This was reflected in the qualitative phase, with carers under 25 often talking of having to defer study, finding it challenging to juggle school work with caring, and considering further education opportunities carefully with their care responsibilities in mind.

Likely due to its accessibility, E-learning (e.g. online tutorials) would be the preferred means of learning for the majority of carers, with close to half (47%) of 16-34 year olds citing this. Carers aged 16-24 have the largest appetite for learning, and are most likely to say that part time study (40%) would be preferable for them whilst continuing in their caring role, as well as home tutorial support (24%) and full time study (20%).

### Middle aged carers

Middle aged carers aged 35-49 are the age group most likely to report an effect on their mental health, with three in five saying this has been affected as a result of their caring role. They were most likely to report increased stress (51%), anxiety (40%) and depression (34%) amongst other impacts.

Carers aged 35-49 were also most likely to report an impact on their working life, with over half (55%) saying caring had affected their work, compared to close to a third (30%) of carers aged 16-24 and one in five (19%) of those aged 65+. This is likely to be a result of these groups being less likely to be in full or part time employment due to their age. This was also clear in the qualitative phase, with participants in this age group talking of reducing their working hours as a result of the amount of time spent providing care, and the impact of this on their physical and mental wellbeing.

Middle aged carers are most likely to say that they want additional support with their caring role. They are most likely to report that emotional support would be useful (38%), as well as financial advice and information (29%) and out-of-hours provision (15%). This may be a reflection of the greater pressures faced by those in the middle age years, who may often have dependent children in addition to caring responsibilities. Only one in ten (11%) of 35-49 year old carers

stated that no type of additional support would be useful to them.

In keeping with this, middle aged carers were also more likely to say that training or advice on how to provide care would be useful to them, as opposed to their older counterparts. Sixteen-percent of carers aged 35-64 mentioned that advice on their own mental / emotional health nutritional advice would be useful to them, and one in ten saw use in mentioned that nutritional advice.

### Older carers

Older carers aged 50 and over were the most likely to report the majority of impacts on their physical health. For example, they were more likely to mention feeling tired as a result of caring (37%), experience trouble sleeping (30%), reduced fitness (23%) and back pain (20%). Older carers also reported experiencing increasing difficulty fulfilling their caring role over time, due to decline in their own health due to age – for example, experiencing general wear and tear and feeling tired more quickly.

This age group were less likely to recognise the impact of caring on their education, with just 2% of carers aged 65+ stating this. This was mirrored in the qualitative interviews and groups, with older carers tending to state that they had already met their education goals.

Older carers were likely to find different types of technology useful, with 28% of carers aged 65+ saying that remote monitoring aids are the most useful type of technology.





### **Further Information**

For further details about us, our mission and values, the Board of Trustees and the Executive Team please visit our website or follow us on twitter.

 [futurecarecapital.org.uk](https://futurecarecapital.org.uk)

 [@FCC\\_UK](https://twitter.com/FCC_UK)

**Royal Patron: Her Majesty The Queen**

Office address: Gillingham House, 38-44 Gillingham Street, London, SW1V 1HU