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# Carers and Physical Activity

A study of the barriers, motivations and experiences of unpaid carers aged 55 and over in England



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# Foreword from Helen Walker



The 2011 census found that there are 6.5 million carers across the UK, providing unpaid care for family or friends who have long term conditions, illnesses or need support as a result of being older. Research released in 2019<sup>1</sup> suggests that two thirds of us will care at some point in our lifetime, with all of us having a 50:50 chance of caring by age 50. These figures show just how prevalent caring is and how important the health and wellbeing of carers is in any discussion about public health, and the health of older people.

It has been clear from previous research from Carers UK that many carers face problems with their own health and wellbeing as a result of their caring role but for the first time, this research report provides clear evidence of a route through which carers are at a health disadvantage when compared with their peers who don't have caring responsibilities. Carers are less likely to take part in physical activity and can face significant barriers in doing so.

Carers are also seven times more likely to report feeling lonely always or often compared to the general population<sup>2</sup>. The stories within this report show that loneliness and inability to take part in physical activity are linked and that social contacts are a powerful motivator to both start and maintain activity. The benefits of physical activity are well documented and it is both unfair and unjust that so many carers are unable to take part in physical activity and therefore less likely to access these health benefits. This is especially unfair given that carers' support is valued at £132 billion a year and the health and social care system would collapse without them!

The coronavirus (COVID-19) pandemic has shone a spotlight on the importance of the role of unpaid carers in the national health and social care infrastructure, but they must be given the opportunity to look after their own health and wellbeing as our society continues to deal with the impact of the pandemic. It is more important than ever that local and national stakeholders take steps to address this profound health inequality.

Thank you to all the research participants for sharing their stories and experiences, to the local organisations for sharing their practice examples, to the members of the project professionals' group for their input into the project development, and finally thank you to Sport England and the National Lottery for funding this important research.

I hope that the findings of this research will be used by national and local decision makers to help carers' health and wellbeing and reduce their social isolation by supporting them to take part in physical activity.

Helen Walker Chief Executive, Carers UK

<sup>2</sup> Getting Carers Connected (2019) Carers Week

# **Executive** summary

This research study, focusing on the experiences of carers over the age of 55 living in England, has found that not only is there a clear difference between the activity levels of carers and their peers without caring responsibilities, but that carers face many barriers preventing them from prioritising their own health and wellbeing.

Addressing this profound health inequality and enabling carers to live healthy lives needs to be a part of the national and local prevention agenda as well as strategies for public health.

For those carers who are able to be active, physical activity offers a lifeline, a chance to de-stress and a vital bit of 'me time'. The research findings, carer stories and best practice examples included in this report show that if support is tailored to carers' needs then it is possible for carers to maintain or start physical activity that they enjoy.

But more must be done to ensure carers have the capability, opportunity and motivation to take part in activity. They must be empowered with the knowledge and confidence to prioritise their own health as well as supported to overcome the substantial barriers they may face. There must also be wider systems change to support carers. For example, the provision of high quality breaks that carers can rely on can go a long way to supporting carers to have their own life alongside their caring. As society continues to deal with the repercussions of the COVID-19 pandemic, carers' health must be prioritised and included in recovery plans and strategies at local and national level.

Note that all references to carers in this report refer only to unpaid carers aged over 55 in England. For more information about categories of carers, research participants and methodology, please see the 'About this research' section at the end of the report.

# Key findings



Carers aged over 55 are **less active** than other adults aged over 55

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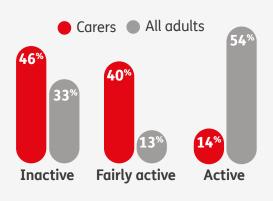
Three quarters (76%) of carers aged over 55 do not feel that they are able to **do as much** physical exercise as they'd like to do



Carers are **more likely** to be **inactive** (46% of carers compared with 33% of all adults)

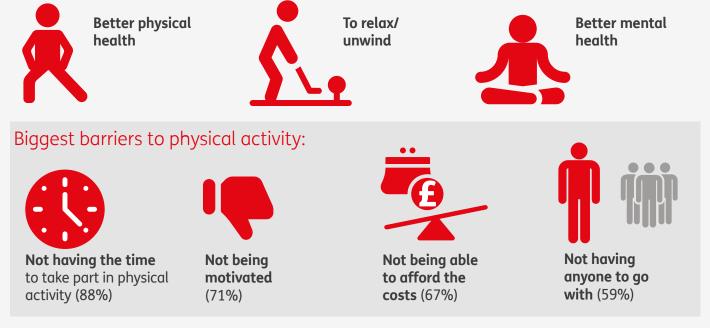


Carers are much **less likely** to be **active** (14% of carers compared with 54% of all adults)



Carers are much **less likely** to be **active** 

# Top reasons carers would take part in physical activity:



# For active carers, a pattern of being active...



### Leads to an increase in:

- Life satisfaction Happiness
- Feelings of worthwhile



Leads to a decrease in: • Anxiety

Although **all wellbeing measures are worse for carers** (regardless of activity level) compared with the general population.

## **Key recommendations**

Organisations across the health, social care and physical activity sectors can all take action:

- Carers should be included as an at risk group in any local or national planning around inactivity and loneliness/social isolation.
- Physical activity providers should become more aware of the needs of carers, including offering flexibility and concessionary pricing for carers.
- National government, local government, Public Health and NHS to see caring as social determinant of health status and act accordingly to mitigate and prevent the health inequalities carers face.

- COVID-19 recovery plans at national and local levels should include the need to improve carers' health and wellbeing, in particular their access to and ability to take part in physical activity.
- National government should increase funding for carers' breaks.
- Carers' Assessments should include ability to take part in physical activity, as part of their assessment of a carers' wellbeing.
- Local carers' organisations should provide a range of physical activity options for carers, specifically targeting the barriers they experience and focusing on behaviour change.

# Introduction to physical activity and key terms



The UK Chief Medical Officer's (CMO) Recommendations released in 2019 state that physical activity is defined as any bodily movement produced by skeletal muscles that requires energy expenditure. Physical activity takes different forms, happens in many settings and can happen for different reasons and purposes.

The CMO's Recommendations further state that 'regular physical activity is associated with decreased mortality and lower morbidity from several non-communicable diseases' and 'adults who are physically active report more positive mental and physical health'.

The recommendations go on to say that taking part in physical activity:

- Benefits health
- Improves sleep
- Maintains healthy weight
- Manages stress
- Improves quality of life

Physical activity is categorised on the basis of the intensity of the activity. Moderate activity is defined as activity where you raise your heart rate and vigorous activity is where you're out of breath or are sweating. Vigorous activity minutes count for double when calculating total active minutes and light activity minutes are not included. In this report people are categorised as being active when their weekly number of active minutes is greater than 150, fairly active where their minutes are between 30 and 150, inactive where they are below 30.

Within the inactive category, carers are 'doing nothing' if they reported doing 0 active minutes across all three categories of activity, they are 'missing the intensity' if they are doing light activity, even in high amounts and they are 'not doing enough' if they are doing some moderate activity but not enough to reach the 30-minute requirement.

A further important aspect of physical activity, especially for older people, is strength and balance. Maintaining muscle and bone strength is vital to maintaining physical function and reducing risks such as falling.

The research findings which follow in this report show that carers are less likely to be achieving 150 active minutes a week and more likely to be in the inactive and fairly active categories compared with the whole population, and thereby less likely to be receiving the benefits outlined by the CMO.

# Carers' activity levels

Three quarters (76%) of carers aged 55+ do not feel that they are able to do as much physical exercise as they'd like to do.

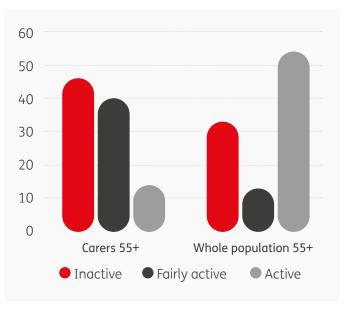
Men are slightly more likely than women to feel that they are able to do as much physical exercise as they'd like to do. As carers get older, they are slightly more likely to say that they are able to do as much exercise as they'd like to do. However, disabled carers, working carers and carers who are struggling financially were all less likely to do as much physical exercise as they would like to do.

#### Table 1: Percentage of carers answering yes/ no to the question 'Are you able to do as much physical exercise as you would like?'<sup>3</sup>

	Yes	No
All	23%	76%
Men	25%	75%
Women	23%	76%
Aged 55-64	22%	77%
Aged 65-74	23%	76%
Aged 75+	29%	71%
Working	22%	77%
50+ h/week	21%	79%
Struggling financially	15%	84%
Lonely	11%	88%
Disabled	12%	87%

22% of all carers aged over 55 agreed with the statement 'physical activity is a big part of my life'. This was lower for disabled carers (17%), lonely carers (17%) and carers over the age of 75 (18%).

Carers aged over 55 are less active than other adults aged over 55 – 46% are inactive compared to 33% of all adults. Carers are more likely to be fairly active (40% compared with 13%) but much less likely to be active (14% compared with 54%). Whole population figures come from the Sport England Active Lives survey May 2018-May 2019, published in October 2019.



Men are slightly more likely than women to be active, which follows the patterns of the whole population. Carers who have a disability themselves and those who are lonely and struggling financially are more likely to be inactive.



3 Numbers do not always add up to 100 due to rounding

	Total inactive	Doing nothing	Missing the intensity	Not doing enough	Total fairly active	Total active
All	46%	7%	29%	10%	40%	14%
Women	46%	6%	31%	9%	40%	13%
Men	44%	9%	24%	11%	40%	17%
Working	45%	5%	27%	12%	41%	14%
Struggling financially	50%	10%	29%	11%	39%	10%
Lonely	55%	11%	34%	10%	35%	10%
50+ hours	49%	8%	31%	10%	38%	13%
55-64	45%	7%	28%	10%	41%	14%
65-74	47%	7%	29%	11%	39%	14%
75+	48%	8%	35%	5%	41%	11%
Disabled	58%	11%	36%	11%	33%	9%

#### Table 2: Categorisation of carers' activity levels according to their weekly active minutes

### Knowledge about activity levels

83% of survey respondents said that they are aware of the amount of physical activity someone their age should do. However, when interview and focus group participants were asked in more detail about recommendations, it was clear that lots of people actually had a **lack of knowledge** about what and how much they should be doing to keep active, and instead were reliant on out of date recommendations. This was especially was common amongst participants who weren't already active.

C Well, I don't know really know how much [physical activity] I'm supposed to do. More than I'm doing because I'm not doing anything." Interview participant

14% of carers said that their **caring role keeps them so busy** that they don't need to do physical activity to keep fit. However, it is unclear if the activity they talk about will be of a sufficient intensity for there to be any health impact.

- C I am very active but don't go anywhere such as gym or swim but I do run around after my son." Survey respondent
- C How can I need more exercise? As a carer, I never stop!" Survey respondent



C I go up and down the stairs. I lift a trolley in and out of the car. I pick my husband up when he falls over. I do three loads of laundry a day. I make a point of taking my husband out often. I never have time to sit down. I'm always interrupted by the telephone, my husband wanting something. It just goes on and on." Focus Group 3 participant

These findings indicate that not only is there work to be done to support carers to be more active, but that education is needed to help carers understand how much and what types of physical activity are beneficial for them to do.

#### Impact of COVID-19 on carers' activity levels

Although the activity levels in this report come from a survey completed in 2019, Carers UK's subsequent research into the impact of the COVID-19 pandemic shows that activity levels of carers in 2021 may be even lower.

A survey from September 2020 found that over two thirds (68%) of carers aged over 55 have reduced their activity levels as a result of the pandemic. Many carers have found themselves under extreme pressure providing significantly more hours of care as services have been closed or reduced, the care needs of the people they care for have increased, or they have been unable to leave their home as much as before. More information on the impact of the pandemic on carers can be found in the 'Caring Behind Closed Doors' report series.

This evidence further underlines the profound health inequalities that carers face and the urgent action that is needed to address this as policy makers deal with the consequences of the pandemic and the recovery.

### Miriam's story

Miriam, 57, used to be captain of a football club, but her increasing caring responsibilities for her parents and children meant she had to give up the sport she loves. She initially started caring for her dad, who was blind and had had two strokes, at age 17, but was still playing football at a good level until 2000 when she had her second child, who was diagnosed with autism at four years old.

"I went to a lower league football club and then an even lower league football club because I just didn't have the time. It was after my mum had the first of many falls that eventually I had to give up because even with support for my children I still needed to help mum and take her shopping and do the cleaning and washing and my mum was in and out of hospital. It broke my heart really, that was all I'd been used to since I was 16. I'd always played team sports and I'd always travelled a lot. That's something I would have loved to carry on but I couldn't because there wasn't the support in place to be able to help."

Miriam's caring role means that she struggles to find time for herself and her interests, alongside looking after her family.

"The problem with caring is that you're actually living two lives. There's your own and the person you're caring for who quite often can't do things for themselves so you're taking into account their appointments, their this their that. Because the physical activity is for yourself, that's the problem and you stop thinking about the thing that made you 'you' and you just go onto auto-pilot. It's all about keeping the person being cared for alright and well cared for. If they're happy, I'm happy."

She feels that if carers had more support and highquality replacement care in place that they could rely on, many more would be able to keep up with the physical activity they enjoy.

"I used to be passionate about what I did and I'm a bit lost really. We still watch the football and we're still season ticket holders, but I do miss it. If someone said to me 'There's a football team and we'll take care of your mum, I would be back on that pitch as embarrassing as it is'. I feel guilty that I'm angry because it's not my mum's fault or my family's fault that we're in this situation and my parents did so much for me."



# Attitudes towards physical activity

Carers demonstrated a variety of attitudes towards physical activity throughout the research, often influenced by their previous experiences, their perceived importance of activity and ability to take part in activity they would like to.

When asked about their attitudes in the survey research, responses suggested that there is an appetite amongst carers to be more active – 87% of carers agreed with the statement 'I would like to be fitter than I am' and only 19% of carers agreed with the statement 'I'm happy with how active I am'.

Only 6% of carers felt that 'physical activity isn't for people like me' and 8% thought that 'the benefits of being physically active are exaggerated further suggesting that there are positive feelings towards activity which could be built on.

# Key considerations around attitudes reported in the survey

- Motivation to take part
- A changing relationship with physical activity over time
- Inability to put themselves first
- Guilt and worries



### Motivation to take part

Motivation to take part in physical activity is key to both maintaining a routine or getting started for the first time.

In the survey research, carers were asked to select their top three reasons for taking part in physical activity, to indicate what their biggest motivations are. The rankings are based on number of times each motivation was selected as part of a carer's top three reasons for taking part. Carers ranked the health and wellbeing effects of taking part in physical activity highly whereas making new friends and trying new things did not rank highly.

# Table 3: Ranking of carers' motivations to take part in physical activity

To have better physical health	1
To relax/unwind	2
To have better mental health	3
To lose weight or improve my appearance	4
To be fit to continue with my caring role now and in the future	5
To be fit	6
To feel good	7
To manage a health condition	8
To sleep better	9
To have fun	10
To feel part of something	11
To spend time with friends or family	12
To increase my self-confidence	13
To make new friends	14
To try new things	15

Men were less likely than women to select losing weight or improving their appearance in their top three reasons but were more likely to say that feeling good was in their top three reasons.

Working carers and those aged 55-64 were more likely than others to be motivated by having better mental health but carers aged over 75 were more likely to select being fit to continue with their caring role.

Carers with their own disability were much more likely to include managing a health condition in their top three reasons.

## A changing relationship over time

Carers were asked about their relationship with physical activity including how this relationship had changed over time. 55% of carers said that they had resolved to be more active in the past but hadn't stuck to it whereas 48% said they used to be good at physical activity/sport.

In the focus groups and interviews, some carers who weren't currently active had a **worry that becoming active would require a big change.** 

CONW I'm extremely unfit so there's an element of anxiety because when I'm going I know it's going to be really hard to do physical activity. When I've been going for a bit I know there will be an element of enjoyment there because I used to enjoy it but at this moment in time, I'm filled with trepidation because I know there will really be a couple of months where I'm not going to enjoy this because I'm so unfit." Focus Group 2 participant

For some, beginning to take part in physical activity had been prompted by a **reflection on their low activity levels** and a desire to change.

C I didn't really do any [physical activity] and then realised I couldn't do what I needed to do like push [my wife's wheelchair]. If you try to push a wheelchair round [where we live] it's really hard work.... And so when I stood half way up the hill gasping for breath, I thought I've got to do something here." Interview participant

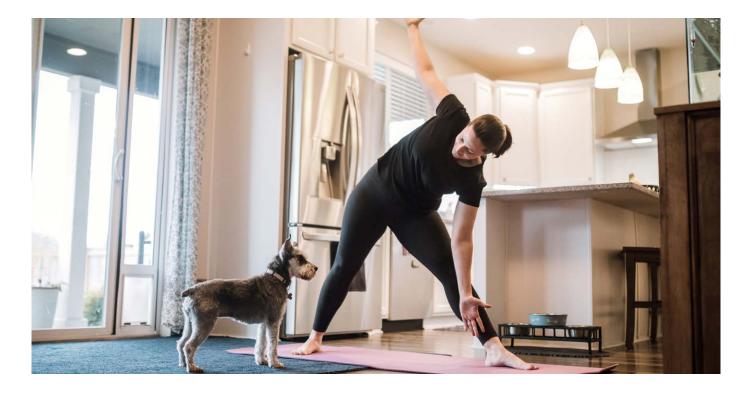
### Inability to put themselves first

For many carers their attitudes towards physical activity are complex, in part because doing something for their own health and wellbeing can feel very unfamiliar when they are used to putting the person they care for first. This leaves some carers **unable or unwilling** to think about **their own health and wellbeing**.

- CC A lot of carers I talk to would make [physical activity] a very low priority, and I think it's very easy to let yourself get so bogged down and get such tunnel vision that it would be the last thing that you'd give any priority to. And I think for people who don't inherently like being active, it must be very difficult indeed when all caring presses down on you. It must be very hard to think I really ought to go and do something active, even if they know it'll make them feel better afterwards." Interview participant
- C Because the physical activity is for yourself, that's the problem and you stop thinking about the thing that made you 'you' and you just go onto autopilot. .... the problem with caring is that you're actually living two lives. There's your own and the person you're caring for who quite often can't do things for themselves so you're taking into account their appointments, their this their that." Focus Group 1 participant
- CC If I've got a few hours free, I think I can take mum for a coffee because she'd like to get out the house. I don't think, I could go to the gym for a couple of hours. So you prioritise the other person." Focus Group 1 participant

This is directly countered by the experience of carers who were able to take part in activity because they had built up the **confidence to put themselves first**.

CC If you twist it on its head. As carers, we're always thinking about someone else and doing things for other people. You can think I'm doing [this for] myself. I'm keeping myself fit and healthy and well as long as I possibly can in order to help my loved one for as long as I can. There's a pay off for them as well as for you. That sort of alleviates the guilt. There's also, you have to give yourself a good talking to sometimes. It feels like being selfish, but you're just doing what every other member of society doesn't think twice about." Focus Group 1 participant



### **Guilt and worries**

For many carers there are a lot of **guilt and worries** wrapped up in their ability to take part in physical activity, although this is strongly linked to a lack of having good quality replacement care which is covered in the barriers section.

- CC It's that word guilt, you're doing something for yourself but all you're thinking is 'Oh but 'I could be doing this for my brother' I could do this' 'I should do that'. You start getting catch-22. You go round and round in circles and I think 'Oh I won't go now''' Focus Group 2 participant
- (When I'm walking) there's this constant 'I could be cleaning mum's house now' and she's all on her own.
  'What if the care workers don't do this, what if this and what if that?'" Interview participant
- C There is a leisure centre, which I do use sometimes but as part of being a carer if I went to the local swimming pool, which is about 10 miles away I could do swimming but then again I'd be concerned about my wife's wellbeing while I was incommunicado. You know, there is that psychological edge. If you do something that you can't keep in touch with someone, you worry. And that's not doing you any good either." Focus Group 2 participant

C The person you're caring for makes it awkward for you to go out. They give you the puppy eyes and then it's bad when you come back because they've been stuck on their own with their own thoughts and stuff and so they're in a bad mood. So sometimes you think is it worth going out?" Focus Group 3 participant

However, in the survey research 45% of carers said that they feel guilty if they haven't exercised in a while. This is just one indication of the competing difficulties carers can often face – feeling guilty taking time away for themselves but also feeling guilty if they don't take that time and aren't active.

The research shows that carers need to be supported to take part in physical activity and that this support needs to consider the complexity behind carers attitudes and be tailored to alleviating worries.

# **GOOD PRACTICE EXAMPLE**

# Activities designed with carers' needs in mind

At Local Solutions in Liverpool, there is a particular focus on making their carers' activities approachable for beginners including older carers. All activities are pitched at an entry level and if a participant wants something more advanced, the centre can refer to other local organisations that can offer specific advanced classes. The format is always a drop-in because they know that carers can't always be there at the beginning and activities are provided free or at a subsidised rate of £2-3 a session. In addition there is a streamlined process for getting people involved, including 1:1 support from Health & Wellbeing Coordinators to increase self-confidence to start activity and induction sessions once a month where current participants attend to share their experiences and encourage others.

At **Carers Leeds**, the weekly Bat and Chat session had been running for a number of years prior to the pandemic giving participants the opportunity to take part in physical activity and meet other carers. The session took place at lunch time meaning carers, including those who work locally, could easily drop in and they make the most of the space they had by setting up a table tennis table in a meeting room. The session was volunteer led and the table was initially bought with a grant, meaning the only ongoing cost was the staff input to oversee and coordinate. For some participants, they took up table tennis more seriously thanks to the opportunity given to try it out.

**Durham County Carers** has expanded the range of physical activity sessions it offers carers as a result of increased interest during the COVID-19 pandemic. Online activities have been hugely successful with many people taking part for the first time now that geographical and time barriers are reduced. The style of activities being organised (yoga and gentle exercises) have been requested by carers and the classes are offered at different times of the day, with the evening classes particularly popular with carers who are also in paid work. There is also a focus on building a community amongst those who take part as the online group call opens 15 minutes before the session begins to allow participants to chat.

**Don't Tone Alone CIC** is a community interest company that delivers innovative, accessible and empathetic training and support for carers. Through a variety of support including online exercise classes, webinars and a mobile app carers are supported to not only be more active but to build healthier habits and coping strategies. During the COVID-19 pandemic, the CIC's support also improved social connectedness at a time of enforced social distance. Their Fit by Phone programme helps those who are digitally excluded to access the same high quality advice and support by phone.





# Paul's story

Paul, 60, has been a carer for his wife for almost 20 years, and after realising he wasn't as fit as he would like to be a few years ago, Paul decided he wanted to make a change with his fitness. A big motivation for him keeping active is that it helps him carry on caring for his wife by making the physical side of caring easier as well as supporting his own wellbeing.

"I didn't really do any physical activity before and then realised I couldn't do what I needed to do to. If you try to push a wheelchair around where we live, it's really hard work and it was whilst pushing my wife's wheelchair one day that I realised I couldn't breathe and so I had to do something. There's a time in everybody's life when there's a realisation that something's got to change and I think that was the day I thought I've got to something."

Paul tried a few activities including circuit training and swimming before joining a running club. His running club is a social community and although their activities paused during the COVID-19 pandemic, he is looking forward to getting back to their regular runs. The schedule of the club makes it easier to fit around caring and he enjoys taking part in runs a few times a week.

"The social side ie talking to someone when you're running is very therapeutic as well. I've built a small group of friends, people who I run with and because we were out every week, we just got to know each other and we got a WhatsApp group and we keep in touch like that."

He's a big advocate for carers taking time for themselves to look after their own health as he personally feels that running has a positive impact on him by helping his mental health and giving him a break.

"It can be hard to leave someone, but if you can get it into your week, just once a week that will be helpful to the person who's caring, which ultimately helps the person you care for too."

# Barriers to taking part in physical activity

With many carers wanting to take part in physical activity, it is often the substantial barriers they face that prevent them doing so. Any efforts to support carers to become more active will need to alleviate or reduce these barriers.

# Carers reported that the main barriers to them being active were:

- Finding the time
- Being able to afford the cost of activities
- Lack of replacement care
- Their own health and energy levels

In the survey research, carers were asked how much they felt that the following statements about common barriers described their feelings about physical activity. The figures represent the percentage of carers who said that this statement described them at least a little.

#### Table 4: Percentage of carers experiencing barriers which affect their ability to take part in physical activity

I do not have the time to do these sorts of activities	88%
I am not motivated	71%
I am concerned about the cost	67%
I don't have anyone to go with	59%
I am worried about injuring myself or making my health condition/s worse	48%
I don't know what type of activity is right for me	45%
I would feel out of place	41%
I worry about doing an activity and not being very good at it	40%
It's too late for me to get fit	34%
I do not know where to go to take part or where to go for help or information	32%
What I might look like in sports/gym clothing puts me off	30%
I have no way of getting to where the activities take place	28%
I don't like getting or looking sweaty	22%

## Finding the time to take part in activity

The biggest barrier which came up again and again in the research was that carers simply don't feel that they have **time**. Many struggle to fit physical activity in to the time they have and those who do have often fought to **carve out protected time or a schedule**.

- C I find it quite difficult to fit in myself into the day because I'm sat down at work all day and then I go to my mother's. That probably takes up at least two hours in the evening and by the time I go home I'm ready for bed. My whole life now revolves around her. I have to factor that into my day. I used to do yoga and keep fit [classes] and I'd have to do them after work but now the time's not there to do it." Interview participant
- CC It's a matter of seeing whether [exercise classes] are scheduled at a time that's right, in terms of letting the carers in who are going to turn up and so forth. And also if we're talking about something organised by a carer's network... that can take me 45 minutes to get there... I'd rather spend my 45 minutes another way. It's a question of whether it's easily available and fits in with the schedule." Interview participant
- C The yoga I've really set my mind to doing it and unless something happens I set my mind to do that because if I don't, something will get in the way..... But I really, really try and do it and make a point of it, because there have been so many things that I've started and the caring role has just gotten in the way, you know I've just stopped in the end." Interview participant
- CC [My wife] has got a structure. [My running club] is definitely Mondays and Thursdays and that structure is in her mind that she knows that I'm not going to be there. Well if I needed to be, I would; I wouldn't just go out leaving her in a mess, but it's just about being organised really and her knowing what's happening." Interview participant

A lack of time is linked with a **lack of control** over their lives more generally and how they spend their time. Life as a carer can be **unpredictable** and carers can struggle to keep to routines and timetables.

- CC It's very important for [physical activity] providers to understand that we live very unpredictable lives. I belong to a gym with my son and a squash club. With the gym if you want to play tennis you have to book for a certain time, they'll hold it for 10 minutes and then they'll cancel it. They'll penalise you and if you get 3 black marks you can't book them anymore. If you've got someone who has trouble getting out on time that's just hopeless... I just think people have to recognise you can't always get to place A at time A because of your caring responsibilities. It's frustrating." Focus Group 2 participant
- C The day is occupied every single minute we have... we don't leave home; I don't leave home at all." Interview participant
- C I miss [my early morning walks and the difficulty is] needing to be there really at 8 o'clock in the morning roughly, to help mum get up and get breakfast. If I said to her "mum that I'm not going to be there until 8.30 or 9.00", she'd probably start wandering around doing things wrong herself." Interview participant
- I now have to do walking routes where I can get back to the house in 30 minutes to an hour at most. So that means I go to a few different places but only further if I'm feeling brave. I go to those places because they follow a bus or tube route and I can get back quickly. I would like to do some longer walks... I have long beautiful walks in Richmond in mind but there's no get out where I can get back quickly." Focus Group 1 participant
- C I love cycling and would like to do more but hard to fit in as like to go with others and mother's care needs are highly unpredictable." Survey respondent



# Being able to afford the cost of activities

**Cost** was a factor that affected many carers ability to take part in physical activity, especially for those with low incomes and who are claiming Carer's Allowance.

- C A lot of these classes you have to book in advance because the classes get full. So you book and cross your fingers but sometimes if you then have to cancel at short notice you don't get your money back. Since giving up work in March, I'm living on Carers Allowance and there's only so much of that you can do. To then miss a class it stops you booking the next one because you think that if you have to cancel you're going to lose [the money]. It becomes a circle of not doing this or that, even though you want to do it, because it's a lot of money in the first place and if you lose it when you don't turn up." Wendy, Focus Group 1
- CC My problem was that I was having to pay for the [class] I didn't turn up for and for the one I did. They've now waived that because of individual discretion to start with. But now the message has gone out in our carers' hub that others can get this. You try doing that at a private provider and you won't get it. The only reason it happens at my leisure centre is it's part council funded and you can put pressure on local councillors." Focus Group 2 participant
- C My local authority [gym] is very good. I can go in without the people I'm caring for and I can get it almost half price. But they don't advertise that. They advertise that if you're disabled you can get it but not carers. Then when you get the form it says that if you're receiving carers allowance you do get the rate." Focus Group 2 participant
- C I did attend a gym about three times a week up until a year ago. I became a lot fitter and my health improved. I enjoyed the company. However, I had to stop going as I could no longer afford it and my husband was alone at home for too long a time as he is currently housebound." Survey respondent
- CC I wanted to join a walking group to walk and get out in the country to help with my mental health but the cost is too much – nearly £10 for each walk including transport." **Survey respondent**



#### **Replacement care**

A common thread between research participants was **lack of, insufficient or poor quality replacement care**, meaning that they do not feel able to take a break from their caring role.

- C It's ridiculous really, because where I work I'll come out and in 20 steps I'm in the gym. But the problem is...by the time I come out of work I haven't got time for [going to the gym] because I've got to get back for mum's lunch... I think if I had more care, say coming for lunch time, then I could probably [go to the gym] because I wouldn't be clock-watching. There isn't enough care to stretch that way because I need the care in the morning because I'm at work." Interview participant
- CC I would say to support me to be healthier needs is about what there is in place working. Everything that could be done for my mum has been done because I've searched every avenue to make sure it is done. It is in place but it's not being done effectively. The social worker says that mum should be ok without me there. The care package that she has in place should mean that she's ok without me. The reality is that there would be no food in the house, she would be fed food that's out of date, she would be living in squalor." Interview participant

- C I used to be passionate about [playing football] and I'm a bit lost really... We still watch it but I do miss it. If someone said to me there's a football team and we'll take care of her, I would be back on that pitch as embarrassing as it is. I'm passionate and angry... I feel guilty that I'm angry because it's not my mum's fault or my family's fault that we're in this situation." Focus Group 1 participant
- C It would be nice to have someone knock on the door and say 'it's your time for respite' and we're here to make sure she's ok. Someone to make her a cup of tea or have a chat. Just so you know, If I'm away and something happened to her, If the tumble dryer burst into flames, she'd be looked after." Interview participant

A lack of replacement care means that for some people their ability to take part in physical activity was linked with the **ability of the person they care for to take part in activity.** 

Complete (My wife's) physiotherapy's just kind of been dropped, you know I just feel like we're on our own really. And that's quite sad really. The only thing we could do together, as far as I can see, is for me to take her out in the car. But that's not physical activity. Even walking is a problem. She is completely dependent on me, she's completely unstable, so to take her for example from the lounge to the bathroom, I have to take her from the lounge to the bathroom via the chair lift and vice versa... she can't be left alone and I can't take her with me." Interview participant

- We looked for an exercise class that we could do together. She'd been sent to one for elderly people to improve balance and then we went wanted to find one that the we could together after that. We asked at the leisure centre [and they recommended one but it was] loud music and energy levels that made me weak at the knees. So we couldn't do that one and we still haven't found one that we could do together yet." Interview participant
- C I take my wife to the gym. They put her on a machine where they strap her feet to it and the machine goes and it gets her heart rate going. That's good because while they're doing that with her I can do my gym activities." Focus Group 2 participant



## Health and energy levels

A further barrier impacting carers' ability to take part in physical activity was their own **older age/poor health** and/or **lack of energy.** 

- C I'm not young, young, I'm 57. Obviously as you get older, I've got aches and pains that someone 20 years younger would probably feel more fit and active. You know. I'm sort of getting to that age where I'm feeling a bit stiffened up and everything aches a bit more." Interview participant
- C I have ME/CFS. I feel guilty using my energy on exercise ('fun') and also quite worried that I will overdo it and be unable to help the person I care for." Survey respondent

- CC I have severe arthritis, diabetes, mental health problems and heart problems. It is as much of an effort to keep going for my wife so not a chance for exercise anymore." Survey respondent
- CC I'm physically suffering from long term injuries, pain is increasing with age, and attempting to care for teenage grandson on autistic spectrum." Survey respondent

### **Other barriers**

Other barriers affecting carers' ability to take part in physical activity that came up in conversation, but not explicitly linked to their caring role, were the **weather**, transport (especially for those in rural locations) and safety.

- C The weather does help if it's a nice day it inspires you to get out. If it's raining and it's been bad day you just surf the net instead." Interview participant
- C I'd like to do more but by the time I've gotten out and I've caught a bus, it's time taken. It's alright for people who've got a car. But for me the transport is an issue." Focus Group 3 participant
- C I would like to swim but the swimming baths are two bus rides away." Survey respondent
- C I did used to go out [for walks] but now there's undesirables in the park. Last year I got approached by a man and it was quite unpleasant so I've not been out since because it's not very nice." Interview participant

This research shows that there are many interlinking barriers carers experience which prevent them taking part in physical activity or reduce their ability. Whilst some will take substantial work to overcome and go to the heart of the lack of support carers have more generally, some can be more easily reduced with simple changes, for example if carers are included in those eligible for concessions or flexibility is given to carers in booking classes or activities. The 'supporting carers to be active' and 'conclusions and recommendations' sections of this report contain more ideas about how to overcome these barriers.

# **GOOD PRACTICE EXAMPLE**

# Activities for carers and people with care needs to do together

**Dementia Adventure** organises supported dementia holidays and outings, family carer training, as well as supporting organisations to set up outdoor activities. The focus of the charity is to support people living with dementia and their families to continue to get outdoors and remain active, retaining a sense of adventure in their lives rather than becoming socially isolated and inactive which can often happen following the development of dementia. All activities look to support both the carer and person with care needs to take positive risks in their life and keep up with hobbies they love.

**Medway Council** runs dementia friendly tranquil swim sessions every week at one of the council owned leisure centres. By making the activity suitable for those with care needs, carers are also enabled to take part in the activity.



# Janet's story

Janet, 67, looks after someone with chronic, complex mental health problems and she didn't recognise herself as a carer to start with because her own role didn't fit with her image of a carer. Janet feels passionately that professionals who interact with carers – like GPs and council staff – need to be more 'carer aware' and more understanding of the pressures carers are facing.

Janet finds it difficult at times to find the motivation to do physical activity and finds getting started to be the hardest bit.

"As a carer some days are just so difficult. I find exercising in the morning is best for me since I always get too busy and too tired as the day goes on."

Despite these barriers, she has found activities which she is able to fit around her caring role and currently takes part in online dancing and bone strengthening classes which are sponsored by her local authority. She also takes part in indoor walking classes which are freely available on YouTube and can be done in her own living room.

"I really enjoy these activities because they give me a sense of wellbeing and of physical achievement. They also contribute to my feelings of independence and happiness. Also because they are online I can do them at a time to suit me and which fits in with my caring responsibilities. I currently do not have to travel anywhere to exercise."

Janet believes that the importance of supporting carers' physical activity is not just a public health concern, but one with an economic impact.

"We need to make the point to the powers that be that fit carers are those who can carry on caring and will save you a hell of a lot of money."



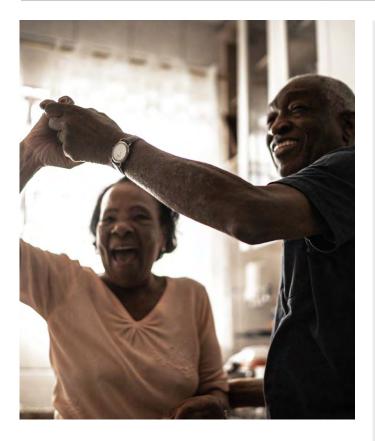
# Physical activity and wellbeing

As was demonstrated in the motivation section, a desire to improve physical and mental wellbeing is a key motivation for many carers as to why they would take part in physical activity. It is well documented that being physically active can not only help people to have better physical health, but it can reduce stress, anxiety and boost mood and energy levels.

73% of survey respondents said that being physically active makes them feel good about themselves. There is also a pattern of increased life satisfaction, increased happiness, increased feelings of worthwhile and decreased anxiety for active carers, although all wellbeing measures are worse for carers (regardless of activity level) compared with the general population. Table 5 includes an average of all the responses to four wellbeing question on a scale from 1-10, matching methodology used by the Office for National Statistics (ONS). Whole population comparisons come from the ONS population data on wellbeing averaged across 2018.<sup>4</sup>

# Table 5: Average response to ONS wellbeingquestions

	Inactive carers	Fairly active carers	Active carers	Whole UK population	All carers
How satisfied are you with your life at the moment?	4.3	5	5.4	7.7	4.8
How happy did you feel yesterday?	4.2	5.1	5.5	7.5	4.8
To what extent do you feel the things you do in life are worthwhile?	5.6	6.3	6.7	7.9	6
How anxious did you feel yesterday?	5.3	5.1	4.9	2.9	5.1



# 4 Accessible from the ONS via: www.ons.gov.uk/peoplepopulationandcommunity/ wellbeing/datasets/headlineestimatesofpersonalwellbeing

# **GOOD PRACTICE EXAMPLE**

# **Health days**

**Enfield Carers Centre** organises health days for carers including presentations from experts, as well as health checks from nurses, free massages and a nutritious lunch. These days take a holistic view on many aspects of health including physical activity but also mental wellbeing, nutrition and giving carers the knowledge to support the health and wellbeing of the person they care for as well.

A similar format is followed by **Carers in Bedfordshire** who also bring carers together to learn for a '5 Ways to Wellbeing' day about various aspects affecting their health in a local community venue. These sessions have a preventative focus by equipping carers with knowledge and ideas going forwards. For example, carers take part in a seated gentle exercise session with activities they can then do at home as well as having the opportunity to relax with sample spa treatments.

Both organisations have been running online events during the pandemic, with their programme edited so it can be delivered online. Many carers who were able to be active shared that they enjoyed the positive benefits of exercise for their wellbeing and this led to the impulse to do more.

C I love yoga. For me, it's more of just trying to do something that makes me feel better in my head, makes me feel less irritable." **Interview participant** 

CO When I do one of my walks I feel quite empowered like I could take on the world, but that's quite extreme. I do feel good when I've done it, there's a certain sense of achievement at the end of it. Then you get a text message and down you go again. Straight after it feels good." Focus Group 1 participant C I did 6 weeks of Tai-chi and from the perspective of stress relief it's actually quite good because it doesn't involve a huge amount of physical activity. You could even do it in 5 minutes, that was the thing I really liked about it." Focus Group 2 participant

These findings indicate that whilst physical activity has a positive impact on carers, it is only one aspect that affects their wellbeing. Any efforts to support carers to be physically active must be part of wider system changes that recognise the impact caring can have on health and the health inequalities faced by carers when compared with the whole population.

## Sarah's story

Sarah, 57, cares for her husband and struggles to find the time for activity alongside her caring role. She works part time for a school who are very supportive of her need to balance caring with work, but that doesn't leave much time for physical activity even though she enjoys the break that it can give her.

"It's not just about the exercise for me. It's about time on my own. I quite like not having to do things for people and just having the thoughts to yourself."

In the past she has looked for flexible exercise options or squeezed activity in when her husband was at an appointment, but these opportunities have been much more limited as a result of the pandemic.

"I can't commit to doing things on a set times at set days and the group of friends that I walk with know that if I text and say, "I know were supposed to be meeting at 9:30. Can we make it at 11:30?" they'll just do it, which is important when you're a carer, it's flexibility."

Sarah took part in Carers UK's pilot project in Autumn 2020 joining an online community, setting herself a goal and trying online activities she hadn't done before, such as tai-chi.

"At one point, I thought, 'Ten minutes tai chi, it's hardly worth it,' but actually, it wasn't about doing the ten minutes tai chi, it was about being outside, the fresh air, the peace. It was all that as well as the exercise."

However, much like many other carers she feels that more can be done to support carers to keep active, especially in times of crisis, and suggests that very short activities which build up could be a good option.

"My husband had a bad fall about four weeks ago and literally I did nothing. I couldn't leave the house, I couldn't go and do anything for about ten days. And I literally did no exercise then whatsoever. I didn't even go out and do my tai chi. And it's that, it's trying to find a way to facilitate that or support people when they're in a crisis time."

"[What would help is] finding exercise that can be done in five minutes, you know, that perhaps you could do in your kitchen while you've put the kettle on because most of us have five minutes in the day. And perhaps you'll have five minutes three times a day and that would add up to a 15 minute chunk."



# Links with loneliness

Previous research has found that 8 out of 10 carers say that they have felt lonely or socially isolated as a result of their caring role<sup>5</sup>. Loneliness features in many people's caring journeys as they find it difficult to maintain social relationships due to the pressures of being a carer.

Throughout this research project it was clear that for many carers there is a link between loneliness and physical activity. In the survey research, only 1 in 10 (10%) lonely carers said that they are happy with how active they are. The survey also indicated that there is a pattern of decreased loneliness for active carers although loneliness levels are higher for carers (regardless of activity level) compared with the general population<sup>6</sup>.

# Table 6: Percentage of carers saying they oftenor always feel lonely

Inactive carers	37%
Fairly active carers	27%
Active carers	22%
Whole England population	5%
All carers	31%

Only 1 in 4 (24%) carers said that they have friends or family who encourage them to take part in physical activity. This was notably lower for disabled carers for whom only 15% said they have friends or family who encourage them and lonely carers for whom the figure was 18%.

In the interviews and focus group, carers were asked about their experiences of loneliness and social isolation.

- C There is a bit of me that knows I've lost myself and I know that's not good. I've lost a lot of friends because they're bored by [me talking about caring] because that's who I am now." **Interview participant**
- C It's shutting that door, pulling the curtains you're in and maybe you don't see anyone for 24 hours. You put the telly or the music on and you're just there." Focus Group 3 participant

C I did [a golfing taster session with a professional] for 6 weeks... that was quite enjoyable. People have said 'why don't you join the golfing club?'. But it's not something you want to do on your own and I don't really know anyone who would go. Golfing might be an idea but I've not really looked into it." Interview participant

While others spoke of the positivity of having a community that encourages them to think about their well-being, whether directly linked to their physical activity or not. This sense of community is also linked with motivation.

- C I've built a small group of friends, people who I run with... and because we were out every week, we just got to know each other and we got a WhatsApp group and we keep in touch like that and if people who do races, they're all waiting to hear how you've done." Interview participant
- C I enjoy the game, I enjoy the banter and the friendship of the people there. I know pretty much all of them by name and you can pretty much say anything to them. You can discuss the weather. Never politics or religion, of course. What drives me to go back is that I know that it's good for Betty – it's good for both of us, actually. If you tuck yourself away, what is it that they say – use it or you lose it, so I think it's critical, essential, that we keep that up." Interview participant
- C It's nice to have people away from the caring. The whole idea for me is just to have some breathing time. You're just talking about light things. The teacher sometimes takes your number and let's you know if the class is cancelled. Nothing too personal." Focus Group 1 participant

A shared experience across some participants was that dogs offer a social cue to take part in physical activity as well as companionship.

Committed to at least taking it out for a few walks every now and again." Interview participant

<sup>5</sup> Carers UK (2019) State of Caring

<sup>6</sup> Accessible via: www.gov.uk/government/statistics/community-life-survey-2016-17

- We got a dog a couple of years ago. He doesn't like other dogs but he's so good for emotional wellbeing, getting out, stopping and chatting to people. You have to take him for a walk. It's not just the physical activity he brings to us, it's all sorts of other things he brings to us as well. He's such a wonderful companion." Focus Group 1 participant
- C The only exercise I get is my little dog in the morning and again of an evening, I meet and speak to other dog-walkers who are sometimes the only people I speak to all day, once my grandchild has gone to school, and my son to work." Survey respondent



# **GOOD PRACTICE EXAMPLE**

#### Walking groups

At **Carers Leeds**, walking groups have also proved to be popular, offering an approachable form of physical activity in the fresh air. The city centre location of the walks means they're accessible by public transport and never too far from a café at the end! During the pandemic the group hasn't been able to meet as usual but has had an online get together and took part in an online marching session.

Carers Stepping Out runs walks in Kent, Manchester, Doncaster, Hertfordshire and Essex with support from local Rambler groups and other walker volunteers. From one meeting place, two walks at different levels are coordinated with the abilities and accessibility needs of those taking part in mind. Carers are welcome to bring the person they care for with them, but many choose to use the walk as a chance to have a break. The organisation is particularly dedicated to reducing the isolation of participants, with plenty of chatting during the walks and a communal lunch provided afterwards. While restrictions were imposed due to the COVID-19 pandemic Carers Stepping Out continued to prevent social isolation by setting up their Stepping Out Staying In service, including WhatsApp groups, Zooms, home workouts, two-way radio shows, newsletters, photo swaps, virtual walks and a book club.

## Darren's story

Now in his late 80s, Darren has been together with his wife for over 60 years. Just over three years ago though, Rebecca developed dementia which has most noticeably affected her with short-term memory loss and has led to Darren needing to care for her increasingly.

Darren recognises the important role exercise plays for them both and they have continued their passion for playing bowls despite Rebecca's caring needs. They have played bowls twice a week for about 14 years.

"You're up and bending down a lot because at the end of each end, you're picking up the mats and the woods and then of course, you're bending down to deliver the woods and standing up again. Then you repeat the process, so it is quite active. When we come home these days, we sort of flop out." For Darren and Rebecca, the sport also provides a vital social outlet and their friendships there are a big part of what keeps them taking part.

"I enjoy the banter and the friendship of the people there. What drives me to go back is that I know that it's good for Rebecca – it's good for both of us, actually. The social side is as important as the game itself."

Having an activity that they both enjoy, where they have a supportive community who understand Rebecca's condition, is essential for them being able to keep active.

"Most of our friends know that she's suffering from dementia and they look after her and they're very complimentary about her because she really is a lovely lady. At the end of the day, we tend to play on the same mat quite a lot so that I can keep an eye on her and reassure as we're playing."

\*Names have been changed.

# Supporting carers to be active

Support for carers to be active needs to address the barriers faced as well as build on the specific motivating factors that encourage carers to take part in physical activity. This section also contains physical activity practice examples from across England which are successfully supporting carers to be active.

# Support from professionals

Some carers shared stories of **understanding professionals** (eg GPs and physical activity providers) who had helped them to gain more knowledge about the physical activity they should be doing.

C I went to the gym because I needed someone to help me put together a programme that wasn't going to create harm. I did start off trying to do my own thing and I was injuring myself all the time. So I'd go along, pull something, and it would be 4 weeks until I could try again. Now I go and see the man who looks after carers at my gym and he'll go through it with you and gradually we move things along." Focus Group 1 participant

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## Technology and digital access

Use of technology can be a powerful motivator for carers, especially those who are already familiar with smartphones and apps, helping them to track activity and monitor progress. For carers who struggle to leave the house or cannot be apart from the person they care for, digital access to programmes and activities can really support them being able to keep active.

C I've got one of these fitbits and it reminds me to get up and do some walking around the house at least. I do try to do 10,000 steps but not often. I walk to the shop and back which gets me in that sort of area so I reckon 10,000 steps is doable for someone my age if you can get off your backside to do it." Interview participant C I do a lot of walking videos. There are lots of good [walking videos] on youtube, including ones you can do indoors. .... You can do it on the spot, you don't need a lot of space and you do work up gradually and you cool down. You can do 1 mile, 2 miles." Focus Group 2 participant

# **Financial support**

Cost has been identified as one of the major barriers for carers, especially those with low incomes and those claiming Carer's Allowance. Some carers shared that concessionary pricing from physical activity providers enabled them to take part.

C My local authority one is very good. I can go in without the people I'm caring for and I can get it almost half price. But they don't advertise that. They advertise that if you're disabled you can get it but not carers. Then when you get the form it says that if you're receiving carers allowance you do get the rate." Focus Group 1 participant

# **Carers UK's Pilot Project**

Carers UK completed a pilot project in autumn 2020 in which a small number of previously inactive carers were given access to an online resource hub with information, advice and ideas to inspire and support them to get more active. Participants were also given access to a Facebook group and received weekly emails, with the same inspiring and supportive content.

The pilot findings were promising, with many participants increasing their activity levels and reducing their levels of loneliness. Tailoring messaging around physical activity to carers, including activity suggestions designed to be done around caring were particularly well received but many also need more help with motivation.

However, the findings also indicated that whilst such interventions are useful for carers, broader systems change is needed to improve carers' health and provide them with support.

# **GOOD PRACTICE EXAMPLE**

### At home delivery of activities

During the restrictions associated with the COVID-19 pandemic, many organisations moved their activities online to ensure that carers were still able to take part from home. For example, **Carers Leeds** have been unable to run their usual sessions and instead have organised online activities such as Zumba and tai-chi using the video conferencing platform Zoom. Weekly breathing and relaxation sessions coupled with information giving have also been a good way to keep carers engaged with the organisation and the support on offer at this time.

**West Norfolk Carers** ensured that a wide group of carers were encouraged and enabled to be active during the COVID-19 pandemic by creating wellbeing packs with suggestions for keeping active. The organisation provides some online group activities including yoga and has a Facebook group for local carers to discuss their thoughts and feelings. For people with difficulties accessing online resources, hard copies were sent and telephone support and CDs with workouts were available.



# **GOOD PRACTICE EXAMPLE**

### Subsidised activities for carers

In the **Royal Borough of Windsor and Maidenhead**, the Council funds leisure activities through the Time Out scheme. A Time Out card, which gives carers access to leisure centres for free, is highly valued by those who use it. Carers (including Young Carers) are eligible for the Cards as part of the support offered by the Council. Further information on how to apply for the card can be found by contacting the Council.

# **GOOD PRACTICE EXAMPLE**

### **Collaborations to support carers**

**Southend Borough Council** decided to work on supporting carers to be more active by partnering with Sport for Confidence, a social enterprise based in South East England. Sport for Confidence first ran a series of workshops with carers to establish their needs and the barriers they were facing and using this knowledge, they now coordinate exercise sessions and gym activities in partnership with local carer support groups. Each session has both a trainer and an occupational therapist to ensure carers' health and wellbeing is supported holistically.

Action For Carers works collaboratively with the local Active Partnership (Active Surrey) to support carers to take part in physical activity. During the coronavirus lockdowns this included running Tai-Chi and yoga activities through Zoom, funded by the Sport England Tackling Inequalities Fund. Action for Carers has also been working closely with Surrey County Cricket Club, Surrey Football Association and Surrey Rugby as part of the Surrey Carers Sporting Collaboration to explore new ways to enable more carers to participate in sport.

# **Conclusions and recommendations**

Michie et al's<sup>7</sup> COM-B framework suggests that a behaviour change can only take place when an individual has the capability, opportunity and motivation to do so. These three factors must come together. This research shows that carers' **capability** to take part in physical activity was increased when they have the knowledge about what activity they should be doing, confidence to put themselves first and understanding of what works for them. Carers' **opportunity** to take part in physical activity was affected by a lack of time including a lack of control over their time and the unpredictability of their lives, but could be increased with tailored activities to overcome the barriers as well as social cues and a supportive community that encourage them to take part. Carers' **motivation** levels might be low to start with but can be positively influenced by the relief and mental break they find it gives them.

Going forward, it is vital that more carers are empowered with the knowledge and confidence to prioritise their own health as well as supported to overcome the substantial barriers they may face. The positive stories and best practice examples included in this report show that if support is tailored to carers' needs then it is possible for carers to maintain or start physical activity that they enjoy.

However, there must also be wider systems change to support carers. For example, the provision of high quality breaks that carers can rely on can go a long way to supporting carers to have their own life alongside



their caring. As society continues to deal with the repercussions of the COVID-19 pandemic, carers' health must be prioritised and included in recovery plans and strategies at local and national level.

The preventative benefits of enabling carers to be active now and reducing the likelihood of developing health problems in the future indicate that there is an urgent need to invest money and resources in addressing this health inequality. Organisations across the health, social care and physical activity sectors can all take action.

## Carers, physical activity and the future

The clear findings from this report lay good foundations for work in the future to raise the profile of carers and physical activity. Over the coming three years, supported by Sport England with funds from the National Lottery, Carers UK intends to work collaboratively with a range of different organisations, including local and national government, leisure providers, voluntary organisations and carers. We intend to raise the profile of physical activity and carers, encourage positive action to make physical activity more possible for carers, fitting in with their needs as well as deliver practical support directly to carers, through volunteers and to carers themselves. Many of the solutions offered are not necessarily resource intensive, but have positive impacts, are measurable, and are chosen and shaped by carers themselves. Carers working with us on this project, including the pilot project, have given us valuable insight into the challenges, barriers and the positive benefits physical activity can make to their lives in a number of different areas where this is not just about health and wellbeing, but also about reducing carers' loneliness and isolation. Together we can make life better for carers.

7 Michie et al (2011) – The behaviour change wheel: A new method for characterising and designing behaviour change interventions.Implementation Science volume 6, Article number: 42 (2011)

### Recommendations

In order to ensure that carers are able to take part in physical activity, and are supported to look after their own health and wellbeing, Carers UK recommends that:

#### Local government

- Ensure that any COVID-19 response or recovery plans include the need to improve carers' health and wellbeing, in particular their access to and ability to take part in physical activity.
- Include ability to take party in physical activity in Carers Assessments as part of the Care Act 2014 welfare principle.
- Provide grants for equipment and technology, access to classes as well as replacement care to enable carers to take part in physical activity.
- Include physical activity in any planning and commissioning concerning carers, especially any local carers' strategies.
- Include carers as an at risk group in any local planning around loneliness and social isolation, including strategies to improve physical activity as mitigation.
- Work in conjunction with other organisations to see caring as a determinant of health status and act accordingly to mitigate the health inequalities carers face.
- Encourage any leisure centres or physical activity providers in the area to be carer aware.
- Make any local cycling and walking strategies inclusive of disabled people and carers.

### Public health

- Work in conjunction with other organisations to see caring as a determinant of health status and act accordingly to mitigate the health inequalities carers face.
- Include carers as a group at risk of low activity levels in any local or national planning around physical activity.
- Include carers as an at risk group in any local or national planning around loneliness and social isolation.
- Raise awareness amongst carers of the importance of taking part in physical activity by empowering them with information and the confidence to prioritise their health by producing carer-specific resources.

# Physical activity providers eg Leisure Centres and gyms

• Be more carer aware and carer friendly offering discounts, concessions or subsidies, especially to carers with low incomes and those claiming Carer's Allowance.

- Train staff to be carer aware to help identification of carers and signposting to other community support.
- Offer extra flexibility to carers in booking classes, understanding that things are more likely to happen outside of their control.
- Ensure that physical activity classes, equipment and premises are accessible for people who are disabled, older or who have other care needs.
- Celebrate the role of carers in the local community by taking part in annual awareness raising activities for Carers Week and Carers Rights Day.

# Local carers' organisations

- Provide a range of classes and activities focussing on physical activity, including digital and at home provision for those who cannot leave home due to their caring responsibilities.
- Include physical activity in any work to mitigate the loneliness and social isolation carers experience.
- Include ability to take part in physical activity in carer's assessments as part of the Care Act 2014 welfare principle, where commissioned to run assessments.

## National government

- Provide an urgent package of support for unpaid carers in the form of an extra payment of £50 per week to be used flexibly for essential breaks to enable them to continue caring.
- Work in conjunction with other organisations to see caring as a determinant of health status and act accordingly to mitigate and prevent the health inequalities carers face.
- Ensure that the new National Institute for Health Protection takes action to support carers' health and reduce loneliness.

## NHS

- Work in conjunction with other organisations to see caring as a determinant of health status and act accordingly to mitigate the health inequalities carers face.
- Ensure that the roll out of social prescribing is inclusive of carers by training link workers to be carer aware.
- Put in place systems and processes, and to have regard for carers and signpost them to support as early as possible in their caring journey.

# About this research

This mixed methods research project included a quantitative phase consisting of analysis of over 2,000 responses to the State of Caring 2019 survey as well as a qualitative phase including focus groups and interviews with 37 participants. This was followed by a pilot project, testing the ideas from the research with 27 participants.

- The funding through the Better Care Fund available to CCGs and Local Authorities should be at least doubled from £130 million to £260 million in 2020/21 and trebled in subsequent years.
- This funding should be ring-fenced this would ensure it does not get lost within local budgets and it is used for the intended purpose.
- Councils and CCGs should have to report their planned spending on carers' breaks within their Better Care Fund plans to strengthen the spending requirement.

## State of Caring 2019 survey

A total of 2,164 respondents aged over 55 in England responded to the State of Caring survey between February and May 2019.

Compared to the carer population as a whole, respondents to this survey were more likely to be female and caring for a high number of hours every week.

Of respondents to the survey:

- 75% identify as female and 24% identify as male.
- 23% consider themselves to have a disability.
- 61% are aged 55-64, 28% are aged 65-74 and 11% are aged 75 and over.

- 4% described their ethnicity as black or minority ethnic.
- 2% are lesbian, gay or bisexual.
- 7% also have childcare responsibilities for a nondisabled child under 18.
- 26% are in paid work (40% full-time and 60% parttime) and 41% are retired.
- 35% have been caring 15 years or more, 13% for between 10-14 years, 23% for 5-9 years, 26% for 1-4 years and just 4% have been caring for less than one year.
- 48% care for 90 or more hours every week, while 18% care for 50-89 hours, 22% for 20-49 hours and 13% care for 1-19 hours a week.
- Most (78%) care for one person, 16% care for two people, 4% for three people and 1% care for four or more people.

As not all respondents completed every question in the survey, a number of the figures given in this report, including those presented in the 'About this research' section are based upon responses from fewer than 2164 carers. This, together with the sample sizes of different groups, should be taken into consideration when reading the results.

### Focus groups and interviews

12 interviews and three focus groups took place between December 2019 and January 2020 as part of this research. The profiles of the 37 research participants can be broken down as follows:

Participants	Interviews	Focus Group 1	Focus Group 2	Focus Group 3	TOTALS
Gender					
Male	6	1	2	1	10
Female	6	6	7	8	27
Age			1	1	
55-64	8	7	3	5	23
65-74	2	0	5	1	8
75+	2	0	1	3	6
Ethnicity					
White	11	6	8	9	34
BME	1	1	1	0	3
Disability					
Disabled	1	1	3	3	8
Not disabled	11	6	6	6	29
Employment status					
Part-time	2	0	2	2	6
Full-time	2	2	1	0	5
Not working	8	5	6	7	26
Caring for					
Parent	4	2	0	1	7
Child	1	2	2	2	7
Sibling	0	1	1	0	2
Partner	6	0	1	0	7
Friend	1	0	0	0	1
Multiple people	0	2	5	3	10
Nephew	0	0	0	1	1
Former carer	0	0	0	2	2
Region					
London	2	3	4	0	9
South East	3	4	3	0	10
Eastern	1	0	2	9	12
South West	1	0	0	0	1
East Midlands	1	0	0	0	1
North East	0	0	0	0	0
North West	1	0	0	0	1
West Midlands	2	0	0	0	2
Yorkshire and Humber	1	0	0	0	1
TOTAL	12	7	9	9	37

### **Pilot Project**

The pilot project took place over 12 weeks from 10th September to 2nd December 2020. 27 pilot participants from across England were given access to an online Carers Active Hub, a Facebook group and received weekly emails with content designed to support and inspire them to take part in more physical activity.

Participants were invited to provide feedback on the resources at the 4,8 and 12 week point and outcomes (including loneliness, activity levels and wellbeing) were measured and compared against baseline figures collected at the project recruitment stage. The profiles of the 27 pilot participants can be broken down as follows (table right):

# Notes on categories of carers referred to in research

- All all respondents aged 55+ living in England
- **Men** all male respondents aged 55+ living in England
- Women all female respondents aged 55+ living in England
- **55-64** all respondents aged between 55 and 64 living in England
- **65-74** all respondents aged between 65 and 74 living in England
- 75+ all respondents aged over 75 living in England
- Working all respondents aged 55+ living in England who are also in paid work
- 50+h/week all respondents aged 55+ living in England who are caring for over 50 hours a week
- **Struggling financially** all respondents aged 55+ living in England who described their financial situation as 'struggling to make ends meet'
- **Lonely** all respondents aged 55+ living in England who said they are always or often lonely
- **Disabled** all respondents aged 55+ living in England who have a disability according to Equality Act 2010
- **Using tech** all respondents aged 55+ living in England who are using some form of technology to help their caring role

# Pilot participant breakdown – demographics

Male      5        Male      5        Female      21        Did not say      1        Age      1        Age      9        55-59      11        60-64      9        65-69      7        Ethnicity      25        BME      20        Disability      21        Disabled / Long-Term Condition      5        Not disabled / LTC      22        Employment status      2        Part-time      3        Full-time      2        Furloughed      1        Mot working      2        Parent      4        Child      1        Sibling      0        Parter      6        Friend      1        Multiple people      0        Nophew      0        Former carer      2        South East      5        East Midlands      2        North East      1        North West      4 <tr tbody<="" tr="">  &lt;</tr>	Gender	
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West Midlands6Yorkshire and Humber1	North East	1
Yorkshire and Humber 1	North West	4
	West Midlands	6
TOTAL 27	Yorkshire and Humber	1
	TOTAL	27

# Carers and physical activity

A study of the barriers, motivations and experiences of unpaid carers aged 55 and over in England

Supported by:





Across the UK today 6.5 million people are carers - supporting a loved one who is older, disabled or seriously ill.

Caring will touch each and every one of us in our lifetime, whether we become a carer or need care ourselves. Whilst caring can be a rewarding experience, it can also impact on a person's health, finances and relationships.

Carers UK is here to listen, to give carers expert information and tailored advice. We champion the rights of carers and support them in finding new ways to manage at home, at work, or in their community.

We're here to make life better for carers.

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