



# CARE FOR CARERS

report 2019



The Care for Carers project provides a range of support to carers including one to one support, group support and respite weekends and days.

Carers often connect with the service at a time of crisis and the project provides a wide range of practical and emotional support that helps them in their caring role.

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# Care for Carers project

The Care for Carers project is part of an Ageing Better partnership funded by the National Lottery Community Fund's Ageing Better programme which started delivery in 2015. The project is delivered by Carers Isle of Wight (Carers IW) and the service also receives funding from the Isle of Wight Council.



**C**are for Carers provides support to carers across the Island. Each carer who connects with the service receives an initial assessment. They are then allocated a Key Worker. Wherever possible this remains the same for the duration of their time with Care for Carers. Once assigned a key worker the project contains the following elements:

- One to one support - this is provided in the home through face to face sessions or over the phone. These sessions are there to support the carer and their frequency and duration depend on the wellbeing of the carer at any given time.

- Respite care - they provide a range of opportunities for carers to have time away including weekends away and intergenerational opportunities.

- Groups and informal activities - a range of different activities, often identified and led by the carers. They also offer drop in sessions and sessions with a particular focus e.g. wellbeing.

- Training - they provide carers with practical training around manual handling but also insights and training around how their caring role may evolve.



# About Care for Carers

Care for Carers provides one to one and group support to carers. The project is solely focused on the needs of the carers. Carers connect with the service in a wide number of different ways. 35% of carers connect following a referral from their GP, a further 12.5% connect following a referral from another health professional and a further 12.5% from Adult Social Care. The remainder have been told about the project from a friend or family member or another service in the voluntary sector.

Once the carer has connected with the service they are given an initial assessment and a key worker is allocated to them. The key worker will then undertake an initial visit. Depending on the level of crisis this will either be immediate (sometimes the same day) or at an agreed time. All carers are offered the opportunity to attend a drop in or other session if they want support prior to this visit.

Following the initial visit a programme of support is then provided to the carer. This can include one to one visits, telephone support, respite sessions, group sessions or encouragement to attend drop-ins. The support is tailored to the needs of the carer. It is open-ended but cases are subject to regular case supervision.

## About Carers

Carers are the often overlooked and unsung heroes of the health and social care system. It is estimated around 1 in 9 people on the Isle of Wight is providing unpaid support in a caring role. Nationally, around 10%<sup>1</sup> of carers are in receipt of carer's allowance. However, once the carer or cared for person is in receipt of the state pension, this benefit ceases.

The economic value of carers to the UK is estimated at £132 billion per year. To help place that figure in context, the whole of the NHS budget in England for 2019/20 is £125 billion. The number of carers is also set to increase with the number rising by 30% by 2030.<sup>2</sup>

Despite the huge benefits carers bring to society this vital role is often overlooked when care packages and support are put together for the cared for person.

*“Caring is 24 hours a day for most carers, many will function on 2 or 3 hours sleep because they are disturbed throughout the night.” (Stakeholder)*

The absence of an automatic focus on the carers gives the potential for carers to enter crisis situations.

*“We see so many carers who manage and manage and manage and then fall into crisis.” (Stakeholder)*

The reality of life as a carer is also complicated. Being a carer can bring a wide range of emotions in any one day from guilt to satisfaction and from anger and frustration to contentment.

*“You don't know what you are going to be facing, are you going to wake up and there is a bed full of faeces that has to be cleaned up because the carers won't be there for three hours and the earliest they can get him out of bed is 10.30am in the morning but he is used to rising at 6am.” (Stakeholder)*



## CARE FOR CARERS DELIVERY

Common among carers is the complex feelings they experience guilt and loss of identity.

*“Imagine your life as it is now and then take all of it out including you, all that is you including your identity.”  
(Stakeholder)*

Carers need support as much as the cared for person does. The more support the carer can receive the more chance they can remain in their caring role.

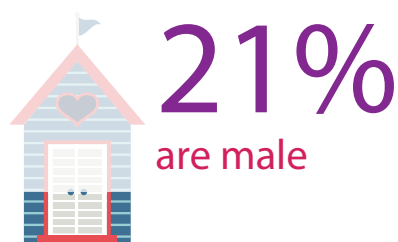
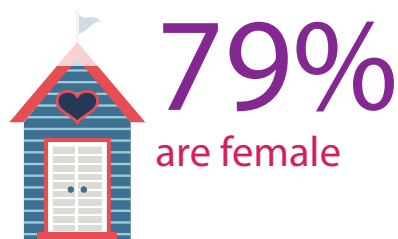
**1** 840,000 people are in receipt of carers allowance against 7.5 million people in a caring role (DWP Benefits Statistical Summary)

**2** [www.carers.org](http://www.carers.org)



## Participants and Reach

Since April 2015 Care for Carers has reached 1,180 new participants. The open ended support means some participants have been involved since the project began. Care for Carers average around 300 new participants each year.



The project reaches a wide range of ages



Carers are by definition providing unpaid support to someone who without it would not be able to cope. However, carers themselves who are supported through this project experience a wide range of difficulties;





**31%**  
are disabled



**35%**  
have mobility problems



**52%**  
are experiencing pain or discomfort



**30%**  
find it difficult to carry out normal day to day activities

Carers themselves have their own frailties and challenges. These can then be exacerbated by their caring responsibilities.

*“One carer supported by the project is in need of a double knee replacement. She has cancelled the operation several times because of her caring responsibilities, she has been told they will not now operate on her.”  
(Stakeholder)*



**60%**  
of carers involved in this project also experience anxiety or depression

Carers can also experience a loss of control. This can include a loss of control of their own environment with carers coming to the house at a range of different times.

*“How do you plan your day when you are stop start all the time.”  
(Stakeholder)*

Because of their caring responsibilities many carers find it difficult to leave the house and lose contact with their wider network of friends. This can lead to people becoming lonely and isolated. On average, carers involved in this work scored themselves as 2.90 on the De Jong Gierveld loneliness and isolation scale, with 0 being least lonely and 6 most lonely. This compares to a score of 1.80 across the older Island population, showing that the project is reaching people who are lonelier than the average older population on the Isle of Wight.

Wellbeing levels are also low, with an average score of 20.70 being reported for the Short Warwick Edinburgh Mental Wellbeing Scale (SWEMBS) (7 being lowest levels of wellbeing and 35 high levels). When compared to a national dataset compiled by the New Economics Foundation, this score is in the bottom 20% of the population and is rated ‘poor’.

The baseline data helps show the carers involved in this project are isolated and have poor wellbeing. They are also often managing a wide range of their own health conditions while undertaking their caring role.



# Support provided

Care for Carers provide a person centred bespoke offer to the carers they connect with.

Carers connect with the service through a wide variety of different routes. Once the carer connects with the service, the listening starts. This includes a phone call and a chat to understand the issues. They also make an appointment to visit. Where they can, they like this to be in the home as it helps give an insight into the carer's life.

During these visits they have discussions about the caring role. This might include getting a carer to walk them through a night or to work through a full 24 hour period to help them understand the practical challenges that the carer is facing. After this meeting a programme of support is agreed. This may include one to one visits, telephone calls, group work or drop-in sessions.

It might also be at this stage Care for Carers shares the range of options that might be available to them and no specific support is provided. This is a key part of helping to build trust with the carer so they feel able to call on Care for Carers when they need it. The key aim of the first visit is to get a sense of what the carer's biggest worry is and maybe what they hope for. A Care for Carers worker will have around 100 open cases at any one time.

*"You can't wave a magic wand and make it okay". (Stakeholder)*

Over the duration of Ageing Better funding the service has evolved and changed. Carers IW have developed a Carers Centre, providing a physical base they can work from and invite people to. They are also piloting and exploring new ways of working to allow them to reach more people with the limited resource they have. This includes developing peer support, drop-ins and more group work. But

the support carers most frequently access is the emotional support. In addition to the one to one support Care for Carers also provide respite weekends and respite days.

*"The respite weekends are very valuable and worthwhile and give carers a feeling of being cared for."*

They provide groups and drop-in opportunities for carers including a men only group.

*"[The group provides] a warm welcome and an unspoken understanding."*

The training also supports the practical elements of being a carer including moving and handling training and dementia training.



*"[The training] was very informative; I have learnt a lot of useful hints, also meeting other people with many different, but sometimes the same problems. I do not feel so isolated."*

*"It was very helpful on this difficult, challenging journey and realising that every journey is different."*



# What works

## Emotional support

Care for Carers places the emotional wellbeing of the carer at the heart of what they do. This support can help the carer manage their stress and anxiety. It also helps them manage any resentment they are feeling. This one to one support allows them to share and express their feelings.

*“I would say the most important service we offer is the emotional support, the ability to have someone who is just for you.”*  
(Stakeholder)

Providing one to one support requires time, and with high demand for the service this needs careful management. Carers IW have a skilled and professional team that allows them to provide more support in a time of crisis and then step back, whilst also keeping them connected to the service through telephone support or group sessions.

*“Thank you, my husband who has dementia is in a care home; my son is dying of cancer. I know I can just cry or chat and it is such a relief that I can be honest with you.”*

The support can also help the carer by helping to normalise how someone is feeling, and also normalising their experience of it. The support can help someone recognise change is inevitable and the support can help people accept and manage that change.

*“This would have been happening with or without the mental illness, it’s just the mental illness puts more pressure on you to do the things you would normally expect your husband to do.”*

## Responding at speed at a time of crisis

Most carers come into contact with Carers IW at crisis point. Something may have happened in their circumstances that makes them fearful of their own reactions.

They may also have reached a personal crisis point where they don’t know how to cope.

The service has bright yellow postcards to help raise awareness of what they offer and help connect people to the activities they have in place.

Carer Z first came into contact with Carers IW when he was in crisis and they did an urgent care assessment. His wife has advanced dementia and he was receiving no additional support. The carer’s assessment was the first step of a package of care for the cared for person. They now receive 56 nights per year in respite care and a carer attends 3 days per week. This will allow the carer to go shopping or out for lunch. The carer is themselves in their 90’s and has experienced periods of ill health.

## Being in the voluntary sector

The Care for Carers service is in the voluntary sector. This is important for carers as it removes fears that statutory services will be automatically informed or involved in their situation.

Care for Carers works closely with Adult Social Care where that is needed and is appropriate. But being in the voluntary sector allows them to occupy a unique place for the carer. They are a professional service who will support them but they are not part of the statutory service. This is important for some carers who are trying to manage their interaction with Adult Social Care. Care for Carers can offer a more objective view of the different agencies because they are independent of them.

*“That is caring generally, battles with social services, battles with different agencies. Just trying to get something that works.”*



## CARE FOR CARERS DELIVERY

### Providing a wide range of strategies

Care for Carers provides people with a wide range of strategies they can use in their day to day lives. Although the key workers at Carers IW have a whole range of different strategies they can support someone to deploy, they are always mindful of not overloading someone with too much information at any one time. They focus on one or two strategies to explore at a time.

The strategies come from the wide range of skills within the team. They include practical strategies associated with understanding the change a person is experiencing. For example, often people with dementia won't recognise themselves in the mirror and that means they also won't recognise their husband or wife as they are supporting them to get undressed. This can lead to the cared for person to lash out. Careful timing of medication can help manage this. Similarly, taking the cared for person for a drive when they ask to 'go home' can help them recognise they are at home.



Care for Carers is also able to loan Stroke Cats and I-Pads that can be tools that may be soothing or relaxing for some cared for people.

They also provide practical ideas including changing the colour of the toilet seat to make it easier to find, highlighting mashed potato on a plate with ketchup or using brightly coloured cups to help people identify their drink.

They are also able to provide practical advice around how music can help or what might work as distractions if the carer wants some time to watch their favourite TV programme.

Although each of these strategies is on its own quite simple, together they can make a huge difference to a carer's wellbeing. Care for Carers is able to match the strategies to the person because they get to know them

and their individual circumstances through the visits and the discussions at the drop-ins and training sessions.

The successful use of strategies also helps them build trust with the carer. Again increasing the likelihood that the carer will reach out before a crisis develops.





# Care for Carers - the difference it makes

## Improving health and wellbeing

Data from the Ageing Better national evaluation survey clearly shows how the project is supporting carers to improve their health and wellbeing.

It is interesting to note how the support from Care for Carers helps improve the carer's physical health and health state. The emotional support and practical strategies help carers carve out time to consider their own physical health.



45%

of participants have self-reported an improvement in their overall quality of life (using the EQ-5d-EL quality of life index)



60%

have seen an improvement or no further decline (using the EQ-5d-EL quality of life index)



48%

self-report an overall improvement in their health



59%

report either an improvement or no further decline

The improved physical health and support means some carers need to call on the wider support of statutory services less.



31%

report a decrease in the use of health and social care services

The data also helps show how the project supports carers' wellbeing. In particular how it addresses the low levels of wellbeing the carers involved in the project identified at baseline. The support Care for Carers provides helps carers think about and plan for the future and how they will manage.



52%

report an improvement in their wellbeing (SWEMWBS)



70%

report an improvement or no further decline (SWEMWBS)



## THE DIFFERENCE CARE FOR CARERS MAKES



# 84%

feel they have been supported to 'live well'

Data from participants who completed the Ageing Better national evaluation survey and the project's own survey demonstrate how the project is helping to improve clients' health and wellbeing, or prevent further decline:

The strategies Care for Carers provide people with help them cope with the immediate crisis they are facing and manage the situations they are in. This support can often be the difference between someone being able to maintain their caring role and not.

*"It's been a lifeline, thank you. When I hit a crisis, no-one was interested, no-one would visit, but you did. You were calm and professional, but kind and gave me ideas about the problems we had. You went above and beyond. I felt that I could manage and not have to think about a care home."*

One couple had moved from quite an isolated area to within walking distance of the ferry, walking distance to respite care and close to their family. Care for Carers was having a chat and she ended up bursting into tears – he was pooping in the kitchen, he had lit the gas hob under the kettle. They gave her some strategies. This included getting her to get some lights to light the way to the toilet. Changing the toilet seat to a bright colour – putting up some pictures of milk bottles on the fridge door. They also got her to get the waste disposal taken out as he was trying to put his hands down it and they got British Gas to put in gas stopcock in the cupboard to reduce this risk factor. They also lent her a stroke cat to help him sit and relax. They managed to persuade her to take extra day care and overnight respite. Now the carer has more support there is more chance her partner will stay independent for longer.

## Reducing social isolation and loneliness

The emotional support and strategies as well as the groups provide an opportunity for people in a similar situation to come together. This all supports carers to reduce their social isolation and loneliness.

The results from the Ageing Better survey show the substantial impact the project has on social isolation and loneliness.



# 46%

of carers engaged in the service are less isolated and lonely

"I find Carers IW such a help in knowing there is always someone to contact or speak to on the phone. It is lovely to meet other people in the same situation as mine as they understand what you are coping with."

The connections carers make through the groups and through the practical advice provided by Care for Carers also helps increase the number of connections a carer has available to them.



# 33%

of carers have increased social contact with friends and family



# 21%

have increased contact with non-family members

The project's success is demonstrated by 89% of carers who they have worked with reporting feeling the project has met their needs.



## THE DIFFERENCE CARE FOR CARERS MAKES AND KEY FINDINGS

Carer X, cares for her partner who suffers with severe mental health problems, was becoming increasingly frustrated with the mental health services on the Island. A plan of action was to be highlighted on the PARIS case management system for when he relapsed again. However, the plan of action was not adhered to and he was discharged only to be admitted again to A&E after being attacked shortly after being discharged. Following a meeting with the carer Care for Carers communicated with the hospital and was able to highlight the carer's plight to the Clinical Quality Lead and arrange a 1:1 meeting giving the carer opportunity to discuss her complaint and concerns over her partner's treatment. Care for Carers supported the carer as requested and attended the meeting as she felt that she needed some moral support. Following the meeting the carer expressed that she felt like she had finally been listened to and felt confident to attend the follow-up meeting by herself. She also feels reassured knowing that she is not alone and that she is able to contact Care for Carers at any time in the future when she needs the support.

Carer A is caring for her frail elderly mother who has dementia. The cared-for person is fully funded by Adult Social Care and has daily care visits. The carer is herself in her 70's and struggling with her circumstances. Recent visits demonstrated a lot of tension and distrust of Adult Social Care. She says that she cannot go on like this: 'I am not as elastic as I used to be and I am worried about my ability to come back'. Care for Carers provides a listening ear, support, small pieces of advice and, if needed, will help ensure a smooth relationship with Adult Social Care. The support means there is always someone who will listen to what the carer has to say. This in turn builds trust that can help manage relationships.

# Key Findings

## Essential service

Care for Carers is an essential service. They provide support to carers on the Island

who's emotional and physical needs would otherwise be overlooked. Providing this support is essential to helping carers maintain their caring role.

The data collected through Ageing Better shows carers engaged in the project are themselves struggling with health conditions and 60% are themselves experiencing anxiety and depression and at the start of the project their wellbeing is 'poor'.

Care for Carers provides people with one to one and person centred support that helps improve their own personal wellbeing. 52% report improvements in wellbeing.

## Emotional support

Care for Carers is staffed by skilled people who are able to provide emotional support to people at a time of crisis. The team has a set of complementary skills allowing them to reach out to and support carers with a wide range of issues.

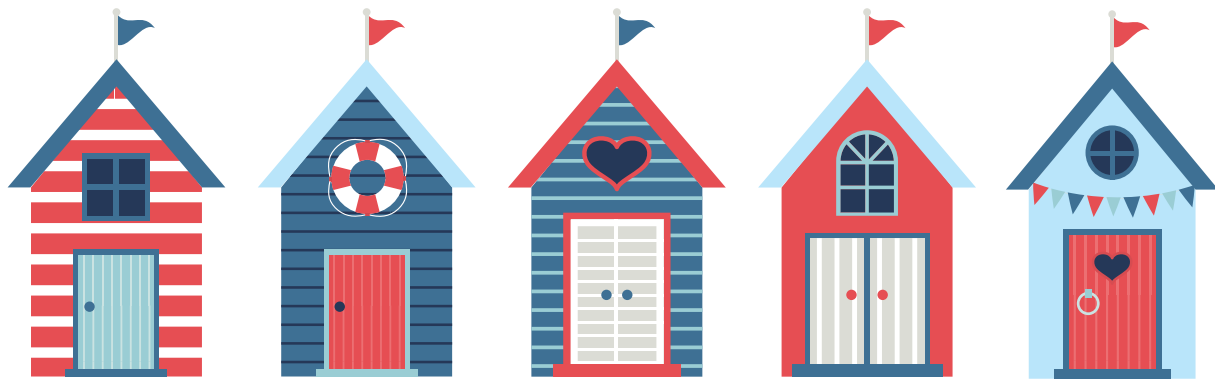
The structure at Carers IW includes regular case supervision. This means the team are constantly considering how they can best support carers whilst also managing the ever increasing demand.

## Voluntary sector

Care for Carers is based in the voluntary sector. The additional funding from Ageing Better is helping them reach more carers and the need for the service is growing. The support helps carers maintain their caring role by supporting their own wellbeing, health and levels of loneliness and isolation. This has a long term benefit to Adult Social Care and there should be ongoing support for the project, even at a time of constrained funding. However, it is important this role is based in the voluntary sector. Carers are often battling with statutory services and this project's position in the voluntary sector allows them to be seen as an objective viewer by both the carer and statutory services.



Beach Huts Vectors by Vecteezy



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**CARE FOR CARERS REPORT 2019**  
Data up to March 2019