

Caring *for the* Carer



*Learning report **summary** / October 2021*

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Background

Between December 2020 and February 2021, the Life Changes Trust, supported by the William Grant Foundation¹, awarded just over £300,000 through a new fund to support unpaid carers of people living with dementia. The funding programme was developed in recognition of the immense pressure on carers due to the COVID-19 pandemic and was based on learning about the impact of small grants from our previous programmes of individual grants for people living with dementia, unpaid carers and young people with care experience.²

As well as social isolation because of restrictions during lockdown, unpaid carers faced a number of challenges, including physical and mental health issues, coping with the emotional toll and economic impact of caring, and a sudden deterioration in dementia symptoms. The Caring for the Carer Fund aimed to support the wellbeing of carers during the pandemic and focused on improving physical and mental health and wellbeing, and supporting carers to cope with social distancing and isolation.

Feedback from unpaid carers revealed that they often experience feelings of guilt and selfishness for thinking about themselves. It was clear that a small amount of funding can bring an enormous sense of value and recognition to carers. A fund focussed solely on supporting carers helped them to feel that they are not forgotten or invisible and that the work that they do is appreciated by wider society.

1 The William Grant Foundation kindly contributed £25,000 to the Caring for the Carer Fund

2 <https://www.lifechangestrust.org.uk/individual-awards-scheme-evidence-and-learning-and-the-Keep-Well-Fund-for-Young-People-with-Care-Experience>

This funding programme supports one of the Trust's five investment priorities for people living with dementia and unpaid carers, **'I am empowered to do the things that are important to me'**. These priorities underpin the Trust's vision that all people living with dementia and unpaid carers in Scotland are valued as full and equal citizens, able to live good quality lives and receive the right support when they need it.³ The Fund aimed to support the wellbeing of unpaid carers during the pandemic and focussed on the following three outcomes:

Coping with social distancing and isolation

Improving/ maintaining physical wellbeing and health

Improving/ maintaining mental health

This summary learning report is based on analysis of all applications to the fund and in-depth feedback from 82 carers, including interviews with 16 of them, reflecting on their experiences of applying for a Caring for the Carer grant. It highlights the benefits of a personalised small grants approach to supporting unpaid carers of people living with dementia and the impact that this approach can have on physical and mental health and social isolation.

We would like to thank all of the carers who took the time to write to us and those who kindly agreed to speak to us. We would also like to thank the decision panel members for their time and dedication.

³ <https://www.lifechangestrust.org.uk/sites/default/files/publication/files/Refresh%20Strategy%202019.pdf>

What did carers apply for?

The Trust received 458 applications for funding. A total of 802 individual items were requested within the eligible applications. The total amount awarded was £301,171 with 402 applications (88%) receiving funding. The highest amount of funding requested was £1,038 and the lowest £44.49, with the average grant awarded being £744. Almost half of requests (47%) were for funding of between £900 and £1000, and 24% of applications asked for the full amount of £1000. Thirty-five applicants (8%) asked for less than £400.

There were:

- ▶ **228 requests for items relating to technology**, over half of which were for an iPad, tablet or computer. Other requests included a digital photo frame, wireless speakers, echo show, air pods, a security camera and broadband.
- ▶ **118 items requested relating to garden improvements**. These included: furniture or garden features, such as benches and raised beds; shelters and heaters to improve comfort and increase use of the garden; and plants and pots. Some applications sought to improve accessibility to the garden, for example, replacing old garden stairs, paving, adding a handrail to the garden, installing a ramp and making the garden wheelchair friendly.
- ▶ **101 items relating to home improvement**. Carers requested funding to support adaptations that they needed to make their home safer for the person with dementia. These included installation of downstairs toilets, shower room renovations, underfloor insulation, flooring, wall cladding, a new kitchen and structural engineering drawings.
- ▶ **80 applications relating to exercise equipment and gym membership**. 14 of these requested a treadmill, 10 asked for an exercise bike, 7 asked for outdoor clothing and 5 requested a rowing machine. Other commonly requested items included outdoor bikes, cross trainers and gym membership.
- ▶ **78 requests for home items for furniture, white goods**, especially washing machines and tumble dryers, as well as kitchen equipment, floor cleaners, cookers and mattresses.

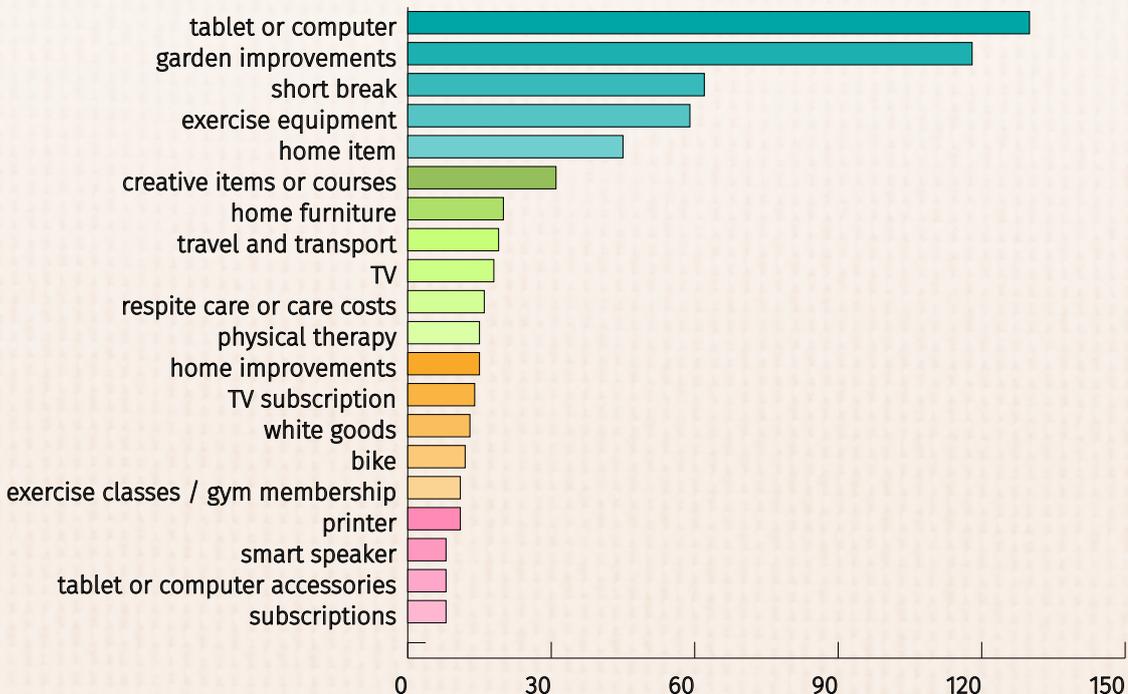
- ▶ **62 applications for support with a short break or respite care.** The majority of applications were to pay for travel and accommodation costs.
- ▶ **31 requests for items relating to creative activities and hobbies.** The most commonly requested items were art materials, followed by craft materials. Other requests included art classes, cameras, musical instruments and sewing machines. The individual nature of requests for jigsaws, a model railway baseboard, a pool table and a pottery workshop demonstrate the importance of having funding that the carer can tailor to their own needs and wishes.

Main categories of items requested

The top 6 categories:



Top 20 Categories





Marion's Story

Marion is in her sixties and has rheumatoid arthritis. Marion's mother has dementia and depression and still lives at home, with a lot of support from her family. During lockdown Marion looked after her mother seven days a week because her brother, who normally helps to care for their mother, was shielding.

The day centres that Marion's mother usually attends were closed, leaving no opportunity for respite. Her care package was also reduced as a result of staff shortages because of illness and cutbacks during the pandemic. Marion's mother is incontinent and because her overnight care was also reduced, Marion had to wash the bedding and change the bed each day. She was also responsible for shopping and paying bills.

Marion's mother was aware that there was a change to her routine during lockdown but she did not understand anything about the Coronavirus and why she was not allowed to go out. This resulted in her mood declining further. Marion tried everything to lift her mother's spirits but this took its toll and, exhausted, she phoned her GP and social services as she was at the end of her tether. Marion missed her friends and being unable to meet up and get a break away from her caring role made the situation worse.

“Nobody seemed to be able to help and I just felt totally alone and trapped in a situation that I could do nothing about. I've had to contact my GP a number of times over the lockdown as I've just felt so low and completely overwhelmed and exhausted with the responsibility. My health has suffered as a result but I just have to keep going for mum's sake as the demands are relentless. It's not the same trying to explain problems over the phone and unless you're going through and living with the situation then nobody really understands how hard and emotionally draining it can be.”



Marion applied to the Caring for the Carer Fund because it gave **“recognition to the situation that a lot of unpaid carers are in and the difficulties that they face”**. She decided to apply for funding to build a summer house in her garden because she thought that it would benefit both her physical and mental health.

“Being in the garden provides a place where I can relax and switch off from everything. I can get away from the phone ringing and forget about all the stress for a little while. I especially like to sit out with a coffee and read or just to enjoy looking at the garden, and listening to the birds. I can only really enjoy sitting out when the weather’s nice but by having a summer house I’ll be able to enjoy the garden even when it’s cold or raining. It would provide a little haven for me. It would give me somewhere to go to escape the demands of everything going on around me and just provide me with some peace and calm.”

Impact of the fund

Coping with social distancing and isolation

Technology

Requests for devices to enable carers to become or stay connected to others during lockdown were common. Laptops, home computers and iPads made it easier for carers to take part in online activities, hobbies and fitness classes which provided external stimulus and a source of relaxation. Technology helped to maintain a connection to the outside world through reading the news and keeping in touch with family and friends. Importantly, carers were able to participate in online carers support groups which provided access to vital peer support.

Often carers felt that a laptop would help to compensate for the closure of support services used by the person they were caring for. A carer who had applied for funding for a new iPad to replace one that he had been using for eight years wanted to use it to see his sons regularly and access websites with activities that he could do with his wife.

"I understand there are Zoom groups run by the Carers Centre, and include training such as internet security, Coffee and Chat groups, and these things could be considered as well. I think this would really help my wellbeing as my wife and I used to be more active. With age and her dementia we haven't been able to get out very much at all and I would like to connect with local supports for both myself and the two of us."

Applications for technology were important for other reasons. Many carers used technology to support them to access information about dementia which helped them in their caring role. It also facilitated attendance at virtual clinical or hospital appointments, keeping carers in touch with health and social care professionals who were also a source of support at this difficult time.

Technology was also useful for practical tasks such as internet banking, food shopping, re-ordering prescriptions and for de-stressing by providing access to meditation websites and apps and online exercise classes.

“I will make such good use of a new laptop. I order a lot of things for my parents via websites such as their frozen meals, medical supplies etc. I also keep in touch with my children via internet and we have group family calls which my parents enjoy joining in with and the laptop will allow us to see everyone well. I also do internet banking etc. and find it a bit tricky on my phone so this will be easier on a laptop. My current laptop is so slow that it takes me ages to do anything on it and time is something I do not have a lot of.”

Technology also provided respite for carers. One gentleman requested an iPod and headphones so that he could listen to music and relax while his wife watched her soaps on TV in the evenings.

“...now I can sit in with her as she watches the TV and enjoy the music that I like on iPod with headphones and we are still together in the same room plus will listen as I go about my daily life looking after her and with the music I choose will give me another interest and at times when feeling down just put the music on, this is going to be a great gift from your fund.”



Maintaining connections through technology

Francesca's Story

Francesca's mother received a diagnosis of early onset dementia just before lockdown. Because social work services were being delivered remotely, there were many delays in getting the support that her mother required. Although Francesca managed to access a Dementia Link Worker, they were unable to visit her mother in her home throughout 2020. Her mother was unable to access any of the groups that Francesca had organised for her and she had been awaiting an OT assessment for her stairs since the beginning of lockdown.

Francesca was trying to monitor any changes in her mother's health remotely in addition to organising social work assessments, professional carers, medical appointments, shopping, cleaning, bills and medication. Knowing that her mother was lonely was adding to Francesca's stress.

“Basically I feel like my Mum and I have been holding our breath, waiting for this to come to an end and there is no end in sight.”

Due to her eye condition, Francesca's mother was no longer able to read, operate the radio or knit. Francesca had noticed that using the phone was becoming difficult and frustrating for her mother and she was concerned that she would start to avoid using it. Francesca applied for funding for an Echo Show, a device that has a microphone and a camera, so that she could speak to and visually drop in on her mother, who has dementia and macular degeneration, at any time. Francesca felt that her mum would also be able to use the Echo Show to listen to the radio, podcasts and audible books, keep up to date with the news, call her friends and family and check the date, time and weather.



“For nearly a year, I have tried to keep my mother motivated, engaged, but I can’t hold my breath any longer. I know that my visits give my Mum new life and I also know that the interminable loneliness and the lack of things to do, is slowly demotivating/killing my mother. The longer this goes on the more stressful it becomes and the more desperate I feel. So to have access to these aids would be like throwing us a lifeline.”

Francesca’s mother had absolutely no experience with any form of modern technology but the Echo Show is voice / touch activated and allows the user to make phone calls, switch on their TV and it can also be linked to put on heating and lighting. It also has sensor motion equipment.

“The Echo Show has helped address my Mum’s isolation/loneliness. She calls us regularly, listens to music constantly and has taken to asking it all sorts of questions. Being able to “see” as well as speak to my Mum, has been a godsend for myself and the rest of my family... Her eyes literally light up at being able to see us during phone calls. So much more meaning to our interactions. It is like being in the same room, truly revolutionary! Even so, now that we have it in place, we can help Mum with any difficulties much more easily, now that she can see and hear us.”

Francesca described the difference that the device has made to her and her family as transformational.

“This has all been truly life changing for my Mum and us, her family.”



Francesca told us that her mother is ***“much more engaged in conversation, whereas on the phone, she was always trying to read from her little notes and would get very distracted and then end up saying “I’m fine” to everything, even though she wasn’t.”***

Francesca created prompt cards to help her mother remember different commands for the device and to personalise her favourite radio stations and singers. One of the most useful features which has helped Francesca with her caring role is the ‘drop in’ facility which she uses to check that her mother is alright, which has provided peace of mind and allows Francesca to see if her mother is ‘up and dressed’, prompt her medication and drinks and remind her about appointments.

“It has reduced the stress of not knowing what was going on, or how my Mum was really feeling, feeling so helpless, plus it allows me to connect directly with her carers/visitors too.”

Garden improvements and furniture

The importance of outdoor spaces in helping to maintain connections and reduce social isolation really came to the fore during the pandemic. Those fortunate enough to have a garden wanted to use funding to improve this space to encourage visitors and create a comfortable space to relax and meet with family and friends in a safe environment.

After nine months of not having visitors to her house or being able to meet friends elsewhere due to worries about her mother catching COVID, one carer received funding to create a safe external meeting area. This provided her with a place to see friends safely and enabled her mother to have more meaningful interactions with family, reducing the carer's worries about her mother being isolated. This in turn had a significant impact on her mental health and wellbeing.

“[The gazebo and heaters] gave me the opportunity to have at least an element of social life and relief from the caring role, out in the fresh air in all weathers and out of the house which is important... so important to take time out and relieve the stresses.”

Not being able to travel or go anywhere for a break made these outdoors spaces all the more important. One carer whose mother was unable to manage being out all day for a day trip wanted to improve her garden so that she could provide a change of scenery where they could visit safely.

“It will be a huge weight off my mind. My parents can come and visit and have a happier time. I would spend more time in my garden. It would make me feel better. I can't invite friends round at the moment.”

In some cases, restrictions during lockdown meant that carers had to wait to get work carried out but some, like this carer who received funding to repair the stairs accessing her garden, told us about the benefits they expected to experience.

“...because of the restrictions we haven’t got the stairs done yet. But we have had the path edged and I’m looking forward to the garden being finished. It will enable me to spend time in the garden safely. The garden has been a place, particularly during the COVID restrictions of movement, where I can relax and have time for myself. The garden offers me a space to exercise and clarify my thoughts and responsibilities. I can’t go anywhere and I joke that I’m going to go on my holidays in the garden in a tent. It will be good to walk up and down to the garden without a hard hat on.”

Improving / maintaining physical wellbeing and health

It was clear from speaking to carers who had applied for exercise equipment that they had experienced real benefits in their physical health. Since there is a close link between physical and mental health and wellbeing, many carers had also seen an improvement in their mental health.

There were lots of requests for gym equipment and home exercise machines which could be easily stored and allowed carers to access physical exercise in the confines of their own home, whilst keeping an eye on the person they were caring for. This provided many carers with reassurance that they could be within earshot of the person with dementia, while also getting a short break to exercise.

Having gym equipment in the home also meant that carers could fit exercise around their caring responsibilities and no longer felt that they had to ‘clock watch’ in order to be back within a certain amount of time to check on the person they were caring for.

“When I use the rowing machine and exercise bike rather than going out on my bike around the roads I just feel like I don’t need to look at my clock so much and I’m a bit more relaxed that dad can get hold of me if he needs me.”

Carers recognised the impact of physical exercise on their mental health and were often using physical exercise to manage their own anxiety and stress, so it was important to be able to continue this with the help of the funding. A successful application for a new bike and cycling shoes gave one carer the opportunity to continue her love of cycling. She described how important this was in helping her to cope with her responsibilities as a carer.

“I have had some real down times during my period as an unpaid carer. It goes without saying that my mental health has been helped due to the improvement in my physical health, increased confidence and forming friendships with people I can trust and share with. [Receiving funding] was fantastic news as it will allow me to continue to maintain my wellbeing, stay connected in this time of social isolation as cycling is one of the things we can do and even in full lockdown we can meet up with one other and to stay physically and mentally well. This has helped me to cope as a carer and stay strong to look after my mum.”

Receiving funding to purchase an electric golf caddy to help him carry his clubs around the course enabled one gentleman to continue playing golf. This was important to him as he had given up golf because of back problems and it was a way for him to recharge his batteries. The caddy meant that he was able to continue playing and enjoying golf which improved his physical and mental health.

“I have sciatica and I was still playing golf ok but I struggled to get the clubs round the course and it was getting me down. It has been brilliant. To start with I was playing 11 golf holes, three times what I was playing, and now I am playing 18 holes again. My anxiety has dropped, I’m a lot calmer. The change in my life has been unbelievable just because of this one thing. It has made a difference to my wife, it helps her. She knows I need to get out, to stress less. Playing golf for one hour a week is absolutely pure bliss.”

Funding for golf club membership allowed one carer, whose husband had early onset dementia, to get a regular weekly break for a few hours to step away from her multiple roles as housekeeper, breadwinner, gardener, driver, parent and decision-maker. The club membership enabled her to get some respite and physical exercise which boosted her wellbeing and let her relax for a while.

“...that time on the golf course allows me to be just a very amateur golfer. I get a real buzz after a round of golf in the fresh air, it is hard to explain. It gives me somewhere to go where I can exercise and keep fit, but it’s also a place where I can go to relax and just forget about all the stresses involved with caring, even for a short time, before it all starts again. Getting away for a round of golf with a friend is so enjoyable and a chance to get away from my worries and fears.”

Carers found that physical exercise helped them to sleep better, which made their caring role a little bit easier and many acknowledged that they needed to start looking after their own health in order to be able to continue looking after the person with dementia. Some carers had struggled to know how to improve their situation without access to respite care or family support and the funding helped them to access items which helped them to be more positive about improving their physical and mental health.

“I applied for an electric bike. It means I can go out with my friend for a cycle just for half an hour and it will be an absolute godsend. It will be lovely just to have half an hour where I can have a bit of time to myself and get some fresh air. Just to get out of the house and blow the cobwebs away. It will be a huge boost to me. In order to care well for mum I realise that I have to make time to care for myself too, something that has taken a long while for me to understand.”



Applications for practical items also helped to relieve physical ailments experienced by carers, ultimately helping them in their caring role. For one man who was suffering from lack of sleep caused by sleeping on a sofa, using the funding to buy a sofa bed helped to improve his quality of life.

“I have been suffering from back problems associated with my sleeping position on the existing sofa. I will now enjoy a decent sleep and my overall health will improve. I could not afford to replace the sofa. Obtaining this grant is the best thing that’s happened to me in the last year and has given me a much better view of coping through the lockdown.”

The flexibility of the funding was key to helping a carer address a health problem which was making her feel ill and adversely affecting her mood. She had received funding for massages but then discovered that she was suffering from vertigo. She was unable to get a physiotherapy appointment through the NHS and was able to use her funding to access a private physiotherapist instead. This meant that her vertigo improved more quickly, which enabled her to cope better with her caring role.

“I’ve still got the funds there to have another session and I’d rather do that than have a massage just now until I feel safe. That has been a great help to me because I was getting really nauseous and bad tempered, and quite depressed actually, because that’s four weeks I’ve had it. I really was quite depressed about it but it feels better now that this is going away and I’m more able to cope. If I hadn’t had the funds there I wouldn’t have even thought about it. I would have thought should I do this?”

Applications for health treatments, such as massages, were common with carers recognising the benefits in reducing tension, pain and stress levels, enabling them to return to their caring role refreshed and with more energy to care. The cost of these treatments can be expensive and some carers used the funding to build in regular sessions that would help them manage long-term.

“I feel these massage sessions will be particularly helpful because my shoulders, arms and back are painful quite a lot of the time, due primarily to the assistance I give to my husband re getting out of a chair and in and out of bed. To be able to have a couple of massages a month, I think will help to ease the pain and allow me to relax.”

“Caring for my wife who has dementia leaves me quite tense at the end of the day – and often during it. An hour at the hands of a qualified masseuse gives much relief which lasts for several days. Tension and pain can result in me being irritable and short tempered which I try to hide but it does surface and is unfair to my wife. The reduction of pain also enables me to enjoy other activities such as gardening and baking.”





Improving physical and mental health

Jack's story

Jack is in his early fifties and, along with his wife, cares for his disabled daughter and his mother, who has dementia. He also has a health condition which causes pain in his neck and back and feels that this has been exacerbated as a result of his caring responsibilities.

“COVID has had a huge impact on my life, all respite stopped along with day services, leaving me with no support. For my mental health I took up an old hobby of cycling which meant I could social distance, keeping my family safe from COVID while giving my mental health a boost and physically it’s not hurting my joints.”

Jack told us that he needed a bike with better gears for the hills where he lived but he would never have been able to afford this type of mountain bike.

“A mountain bike with a lighter frame and better suspension will help me get out and about in the local woodland paths and hill climbs. Cycling is good for my stress and I feel it relieves my back and muscle pains. I can’t do any other sport due to my health condition. My mental health is better after I have been out on the bike.”

He applied for a mountain bike which he described as a ***“life changing gift”***.

“This mountain bike was the perfect bike to get round the woodland paths and up to where I live. The paths can be very rugged and the suspension helps. This was the perfect fit for me. [The bike manufacturer] only make a few M/L frame size and I got the last one in Scotland. I never apply for anything and think this only happens to others. It’s my turn now, what a feeling.”



Improving physical and mental wellbeing and health

Sarah's Story

Sarah is in her sixties and lives with her husband who is disabled and has mixed dementia. Sarah also has health conditions and suffers from anxiety. Sarah's husband used to go out for two hours every week with a paid carer, however this stopped when the pandemic started, due to restrictions on car sharing. Sarah and her husband were also nervous about allowing anyone into their home because of the virus, so they were not keen to continue with this support. Sarah's husband participates in a Zoom brain gym group once a week for an hour. This is the only support they received. Unfortunately, family were unable to help because they are key workers and their jobs made it too risky. The couple felt trapped in their home.

“We used to like to go out for lunch maybe once a week to the garden centre or a stroll to the big park with the dogs but we've been too afraid to go to the big park because it's too busy, especially while the children were about because they weren't at school. We've not been out much at all.”

Sarah felt quite guilty applying for the funding because she had been able to manage up until then. She heard about the funding through the e-newsletter from her local carers centre and decided to check her eligibility.

“I went to the website to look at everything that you did, I was trying to see if I would be eligible in terms of financially or my caring situation but I couldn't find anything that said I wasn't so I thought, well what have I got to lose, I'll just try anyway.”

Sarah successfully applied for materials to continue with her hobby of painting.

I find when I'm concentrating on painting I'm so focussed because the work is tiny, I'm so focussed on it that I don't think about other things when I'm doing it and I know I just need to lift my head and I can see that my husband is fine and I'll carry on. You close out everything else and concentrate on what you're doing when you're being creative. It's a great respite I find for me."

Sarah also had problems with her neck and shoulders and prior to COVID she tried to have a relaxing massage as often as she could to ease the stress. But the cost was sometimes an obstacle. She decided to apply for funding for a monthly massage for one year.

"It was lovely and it really made me feel good. It sounds silly but I felt more patient with my husband after that and it must have been because I was relaxed. But I did find it such a benefit. So, this payment, which I will keep in a separate account, will allow me to enjoy that relaxation every month, bliss!"

As well as improvements to her physical health, Sarah also expected benefits to her mental health, in particular reducing her anxiety.

"This payment will allow me to continue to paint for the foreseeable future. It gives a pattern to my week, provides a focus away from caring and gives me confidence in being able to create something. It is very important to me to maintain good mental health, to avoid increasing stress levels and my own wellbeing, and in order to continue to care for my husband at home for as long as I can. I am very grateful for this funding so that I can continue to care for my husband while maintaining a little bit of space and time for myself without the worry of funding the activities I can enjoy."

Improving / maintaining mental health

For many carers their gardens or outdoor spaces were not just important in keeping them connected to others, but being outside was also important in helping to restore them. A carer whose family had struggled financially during the lockdown after missing out on financial support, requested funding for garden improvements. The garden helped to alleviate the stress caused through sudden loss of employment and provided a place to relax and come to terms with her mother's dementia diagnosis.

"I can't tell you how much difference it has made. I can sit and look at the garden from my living room on a wet day and I can't imagine not having it, it's an extra room bringing the outside in. It's a place I can go that makes me feel calm. When my mum was diagnosed I was resentful and couldn't handle it well... I really struggled and I ended up on anti-depressants. If I didn't have the garden I would have nowhere to direct that bad energy to, it's a release. I can sit out there and close my eyes and I could be anywhere. It's peaceful."



Many carers applied for items for themselves but which would also make their caring role a little bit easier, which subsequently helped to improve their mental health by reducing stress. Sometimes the funding was for something which the person with dementia could get involved in too, an activity they could safely do alongside the carer. In the absence of external activities and events this provided some respite for the carer. One carer who applied for raised beds, compost and a bench discussed the benefits for her and her mother of applying for garden items.

“I am finding there are fewer and fewer things we can do together that does not involve outside assistance or a lot of planning on my part. Pottering in the garden offers a safe activity which makes her feel useful. I can talk to mum about what to grow and it stimulates her which takes pressure off me to find stimulating activities for her. I thought it would benefit mum as well as me. It was to do with her but not totally centred on her. I feel guilty if I leave her on her own. This way it is something for me but she is also close by. It’s also reassuring for me. It is relaxing and it takes my mind off caring. It’s mindfulness really. I can see that mum is ok without having to check on her all the time. It also gives me a haven to go to if I need a break or ‘time out’ without having to leave the house or get in alternative help.”

Many of the feedback letters and emails mentioned how the funding had helped to make life a bit easier for carers because it enabled the carer to get on with doing something enjoyable and meaningful to them whilst also providing peace of mind for them and reassurance for the person they care for.

“I can sit at the table in the dining room and I can see what he’s doing and I can paint at the same time. It’s ideal because it means I am having time to do what I want to do but I can see him at the same time. He can see me so he knows where I am and he can see what I’m doing. It lets me recharge my batteries while I’m doing that and makes me less impatient with him.”

Carers used creative activities to relax and forget about their worries for a short time and were often able to involve the person they were caring for in these activities, sharing experiences which helped to bring them together. Carers welcomed the opportunity to learn new skills and use a new challenge as a diversion from their caring responsibilities.

“It gave me an opportunity to do something for myself within my home and engage my brain in a fun, learning capacity. Playing the guitar temporarily took me out of the world I was living in and transferred me to another world where song lyrics replaced the run of the mill thoughts I experienced day-in-day-out. It was something I could also share with the person I cared for in a happy, productive environment.”

After using the funding to buy a Yamaha digital piano one carer, who shared a passion for music with her mother, wrote:

“It is already making a difference to our lives as it has given both Mum and I a renewed enthusiasm to rekindle our love of music and singing. It provides me with a form of escapism, time for me and an opportunity to progress. It is therapeutic and relaxing. It’s nice to do something that you can get engrossed in and forget all your cares and troubles. It gives you a purpose. When you’re caring, your time is very tied up and there is not much time to yourself. It gives you joy and makes you feel good inside.”

One carer had used art as a form of respite prior to COVID but caring full time for her mother meant that she no longer had time to set out equipment and materials and was unable to leave paint and paintings out undisturbed. Consequently, she was losing interest in art and found that her hobby was becoming more stressful and less enjoyable. She applied for funding for an iPad Pro and pencil to support an art app which would allow her the flexibility to fit art into her caring role and enable her to do it anywhere and at any time.

“The iPad as a standalone art package has been truly amazing. Its portability and ease of use has lowered the barriers to my own hobby, enabled me to clear space within the house and carry out my art in a comfortable setting. Now on a very neat machine I have the freedom to experiment with both drawing and painting at any time and in any location with little effort on my part, which has rekindled my interest and enthusiasm and brought colour back into my life. I assure you that the award has provided the respite and help I was badly needing as well as bringing back the enjoyment and fun of painting.”

A new sewing machine meant that one carer could make soft furnishings and decorative items, which made her feel calmer and helped to manage the stress of her caring role. She was looking forward to the sense of achievement that she would feel with the items she was going to make on the machine.

“I find sewing very absorbing and destressing, for me it is quite a mindful practice and I think it will help me to feel calmer. For me this is so positive, with all the stress and endless challenges, to have something tangible and creative to think about and plan, to shut this stuff down for a bit and get absorbed into some other activity will be really helpful. It will be wonderful to be able to achieve something too, to have some finished products that I have made, and having the machine will allow me to do so much more than I can achieve by hand. I am really looking forward to it.”



Having an opportunity to relax, even for a short time, was important to carers in reducing stress and restoring themselves to face the challenges of caring during a pandemic. A carer who asked for funding for garden improvements described the impact this had on her wellbeing.

“The garden is a sanctuary for me, especially last year when weather was good. My role as a carer has been a huge shock to me, and has taken about a year to adjust mentally. The space in my garden is precious, it is one wee space for me to be on my own, just to relax, put things in order again. Now I will be able to re-do the area. It is small but peaceful and even if the weather isn’t great, I can wrap up and ‘escape’. Part of dealing with the stress I have felt is the ability to have my own space and time, even for a few hours, or just minutes. To have a coffee – feel the sun on my face, breathe!”





Improving mental health and reducing social isolation

Louise's Story

Louise is in her 70s and looks after her husband John who has vascular dementia. COVID means she can no longer meet her friends or attend her fitness classes. Her family is unable to visit and she feels like her normal life is on hold. She is unable to leave her husband for very long or go very far as they both have to isolate. Her husband had three falls in one month and cracked a rib. Louise feels very lonely and worries about supporting her husband. Her mental health has suffered, her stress levels have increased and she struggles to sleep at night. She feels tearful and her brain feels numb at times.

Louise applied for funding for an arbour seat and garden furniture to help support her wellbeing.

“I can sit and read and relax in a sheltered area and get a break from the confines of the house. I love being in the garden but it can be cold and windy at times due to the weather. I believe having a shelter will help me to relax whilst at the same time being in hearing distance from my husband. To have a sheltered space to go to would help my wellbeing as I may be able to enjoy the peace and tranquility in my garden. Watching the birds and wildlife may offer me some assistance with helping my brain to unwind. Some garden furniture will mean that a friend or family member can meet outside whilst socially distancing from me and a chat would be most beneficial for my mental health.”

Although carers often found respite in their gardens or in participating in creative activities, it was difficult during the pandemic to access respite in the form of a short break. It is not, therefore, surprising that many of the applications asked for funding for a short break or to cover the cost of respite care to enable the carer to get some time away from caring. The funding provided many carers with the opportunity to take proper respite by either paying for accommodation and travel costs or to pay for someone to take over caring for a short time.

“I just want you to know how much I appreciate this. I love mum but I need a break. It’s been a very difficult winter, mum in decline, miserable weather and finishing at work. This has given me a boost, one I was seriously needing. My mental health, not the best in the winter, has been declining but this has cheered me up no end. I know, not a big deal in the grand scheme of things, we are still alive, but they are coping mechanisms, stress relievers which no longer exist at the moment. I couldn’t afford it on my own. It gives me something to look forward to. I will come back refreshed and recharged to carry on with mum.”

During lockdown carers were not able to book any respite due to travel restrictions but it was clear from feedback that the opportunity to plan a short break at some point in the future was enough to lift spirits and that the change of environment would provide a space for carers to ‘recharge their batteries’. A carer who received funding for a short break to visit her family told us that she had applied largely to catch up on sleep. She recognised the importance of building in regular respite to support her to continue to care for her husband.

“I think this would help restore my energy levels and give me some valuable space and time to think about some other positive strategies that might help us going forward. Just the idea of going out somewhere, having someone cook my dinner for me and wash up. I will be rational, sane, it will restore me temporarily.”

Carers observed that they were able to relax on a break in a way that they were not able to at home. As one carer said, ***“I think because you have to surrender some control and accept you can only do what you can do.”***

Supporting carers in their caring role

Some carers used the funding for very practical items that would help with day to day caring or would enable them to take a break from responsibilities. One carer bought a mobility chair for her husband, while another used the funding to buy takeaways from a local hotel so that she could have a day off per week from cooking for a few months. A new printer enabled one carer to print signs for her parents to help them around the house, allowing them to live in their home for longer as independently as possible.

“As his sole carer, because I have been diagnosed with Rheumatoid Arthritis and am finding it impossible to raise him from his chair or sofa wherever he is sitting. This was the best thing that could help me right now and I cannot explain properly the difference it has made to both of our lives.”

Carers were able to purchase expensive items, such as kitchen appliances, sooner than they would have been able to without the award, making everyday tasks a lot easier for this couple in their eighties.

“These items I have listed were old and needed replacing to make things easier in the kitchen. I was hoping to replace them in the near future when other funds were available. Now I’ve been able to buy them sooner than expected. Defrosting the freezer has been more difficult recently. The new toaster arrived today, perfect toast at last.”

Funding helped some carers who had found themselves taking on new tasks and responsibilities as part of their caring role. For example, a new laptop made it easier to print out information, access support online and handle household administration. Often the benefits of the item went beyond the carer and had an impact on the wider family as well as the person being cared for.

“It will also help my sister whose son is autistic, she can sit outside and relax. And my mum is in a wheelchair so the ramp will mean she can access the garden easily. It helps everyone. It helps visitors from the family, if they need to go into the house to use the bathroom they don’t need to worry about falling.”



What did we learn about our funding approach?

Delivering a programme of small grants for unpaid carers

Learning from the Individual Awards Scheme⁴ delivered in 2014-15 and 2018-19 demonstrated that ***“a model of a small grant, issued through a simple, trusting and supportive application process, with flexibility to choose and change decisions on spend, allows people to have control and to make decisions that maximise the outcomes for themselves.”*** The approach taken for the Caring for the Carer Fund built on this learning and conversations with projects delivering support to carers during the pandemic disclosed many of the challenges that carers were facing.

Broad eligibility criteria

It was important to ensure that the Caring for the Carer Fund was as accessible as possible to a wide range of carers. This was achieved through having a broad eligibility criteria that allowed carers to apply for anything that would support them with any of the outcomes that the fund focussed on: coping with social distancing and isolation; improving/maintaining physical wellbeing and health; and improving/maintaining mental health.

Often unpaid carers were experiencing financial hardship and the broad eligibility criteria enabled them to use funding to purchase essential items. Evidence from applications to the fund highlights the individual nature of each caring journey and the individual needs of each carer. Any response to the needs of unpaid carers must acknowledge this and provide the flexibility to focus on the outcomes of the carer rather than how this is achieved.

There is still a lot of work to be done engaging with Minority Ethnic communities around dementia, as demonstrated by the low numbers of applications from people who identified as non-white. Previous work carried out for the Trust⁵ identified a number of barriers to engagement including language barriers, misperceptions, inaccurate translations, and lack of cultural awareness. Working with third party organisations who support unpaid carers from Minority Ethnic groups can increase the reach of funding and ensure that unpaid carers from diverse communities benefit from small grants.

4 <https://www.lifechangestrust.org.uk/individual-awards-scheme-evidence-and-learning>

5 <https://www.lifechangestrust.org.uk/publications/evaluation-dementia-projects-minority-ethnic-communities>

“A person-centred approach would acknowledge that unpaid carers are not a homogenous group; we come from all ages, from different cultural and ethnic backgrounds, and with very different caring experiences. Each of us have our own needs, desires, and aspirations, and these cannot be addressed by a one-size-fits-all service.”⁶

Simple application process

The simplicity of the funding approach was important in helping as many time-pressed carers as possible. Carers had the option to submit their application by post or complete it over the phone with a member of staff if they were not comfortable completing it online. The application form and guidance were straightforward and in plain English. Feedback from carers showed that they valued the brevity of the form and the opportunity to describe their situation and what would improve their circumstances.

Involve carers in assessing applications

A decision panel comprising current and former unpaid carers brought deep knowledge and experience-based judgement to the process, much more than would be available with a traditional panel consisting of only funding staff. The guidance materials emphasised that applications would be assessed by current and former unpaid carers of people with dementia and their advice was particularly helpful to Trust staff when providing feedback to unsuccessful applicants. The flexibility of the decision-making process allowed the panel members and funding staff to incorporate learning as they went along to ensure that the process was constantly refined.

6 <https://www.gov.scot/publications/independent-review-adult-social-care-scotland/> Shubhanna Hussain-Ahmed

Flexibility in use of grant

The importance for carers of having flexibility in using their small grant was very clear, particularly because during the pandemic, carers' needs could change very quickly. Being able to change a funding request in light of changed circumstances, such as the death of the person they were caring for, was key to ensuring that carers were able to meet their specific needs through the Fund.

Uncomplicated and fast payment

The turnaround for payment of funds was quick and uncomplicated. After the decision meeting, applicants were contacted as soon as possible to inform them that their application was successful. They were invited to contact the Trust directly to provide their bank details, and payment was made at the earliest opportunity. Successful applicants were not required to provide receipts or other evidence of appropriate spend – the grants were awarded with complete trust.

“I think I was a little bit surprised that you didn’t require the receipts but that adds to the simplicity of it, the fact that there is a funding application and then you are just expected to say that you got it. It’s amazing that we do feel trusted.”



What did we learn about supporting carers during a pandemic and beyond?

Coping with social distancing and isolation

Funding for technology often provided opportunities for carers to connect or reconnect with family and friends, carer support groups and online activities helping to reduce social isolation. Although online support was not suitable for everyone, it became a lifeline for many carers during the pandemic. Ensuring that carers have access to funding and technology to enable them to stay connected is key to reducing social isolation and supporting mental health.

At a time when gardens became a focal point for people to meet, the fund also provided many carers with the means to improve access to their gardens and outdoor spaces, enabling them to meet safely with other people and maintain social connections that could support them with their caring responsibilities. COVID restrictions highlighted the importance and value of face-to-face connections for carers and it is important that carers have the time and space to foster these relationships which help them to continue with their caring role.

Improving/maintaining physical wellbeing and health

Being able to buy exercise equipment to store at home allowed carers the opportunity to fit exercise around their caring responsibilities, reducing stress levels, improving sleep patterns and improving their physical and mental health and wellbeing. Exercise was also a respite for many carers.

Carers are aware of the importance of maintaining their own health to be able to continue caring for the person with dementia. One of the key benefits of the fund was providing the financial means for carers to reduce stress, for example, by way of massage treatments, counselling sessions or respite through a short break or through covering the cost of care. Flexibility in self-directed support payments would enable carers to look after their own health and prevent them from reaching crisis point.

Improving/maintaining mental health

Carers told us that the fund helped them to feel acknowledged, valued and appreciated. It gave carers hope that they had not been forgotten and often provided a boost in difficult circumstances. We learned that carers want to be given recognition for the difficult job that they do and that feeling valued and listened to can foster a sense of wellbeing.

Funding gave carers the opportunity to pursue hobbies that had been laid aside due to time or financial constraints, providing a coping mechanism to deal with the challenges presented during the COVID-19 pandemic. Many of the items that carers applied for related to creative activities which provided a means of relaxation and a way to manage stress and anxiety. Carers benefited from the respite provided through these activities, they enjoyed learning new skills and having something for themselves. Many carers benefited from outdoors activities in the garden, relishing fresh air and a connection with nature which served as a restorative balm.

The findings of a survey carried out by the Health and Sport Committee at the Scottish Parliament in August 2020⁷ found that during the pandemic respondents were unable to use personal budgets 'to buy additional equipment such as a tablet, or art supplies in lieu of workers being available or to 'pay a family member' when carers were not available.' The impact of the Caring for the Carer Fund demonstrates the importance of a flexible approach to funding focussed on outcomes in providing carers with access to what they most need to support them.

Carers need information and signposting to financial support

We have learned that many unpaid carers are struggling financially and are relying on funding from charity to fund essential items to support them in their caring role.

Many of the items that carers applied for, including adaptations to their homes, should be provided through statutory resources. Financial support as part of post-diagnostic support for carers would support carers in their own right to continue in their caring role.

7

Carers need information, especially about their rights

Many of the carers who applied to the Caring for the Carer Fund were unaware of how to access support or funding and did not have an Adult Carers Support Plan in place. Research carried out between 2018 and 2020 found that many unpaid carers are unaware that it is possible to access SDS⁸. This has significant implications for the commitment in the Dementia and COVID-19 Action Plan⁹ that relates to ensuring that carers are aware of and can access the support they are entitled to and are aware of their rights under the Carers (Scotland) Act 2016.

Carers need post-diagnostic support and not just for one year

The findings from the funding programme highlight the gaps in delivery of post-diagnostic support for unpaid carers during COVID and illustrate how carers are still not considered in their own right. During the pandemic local community organisations were able to respond more quickly and provide a breadth and depth of support that statutory organisations were unable to do.¹⁰ To ensure that the needs of unpaid carers and the person they care for are met at the right time and in the right way requires a broader approach to the delivery of post-diagnostic support, at the heart of communities, with collaboration between statutory and voluntary/community organisations. Dementia Friendly Communities¹¹ and Meeting Centres¹² are examples of how support can be delivered within communities by a range of partners working together to improve the lives of people living with dementia and unpaid carers.

8 <https://www.sdsscotland.org.uk/mysupportmychoice/>

9 <https://www.gov.scot/publications/dementia-covid-19-national-action-plan-continue-support-recovery-people-dementia-carers/>

10 https://www.lifechangestrust.org.uk/sites/default/files/publication/files/BOTH%20PROGRAMMES%20COVID-19%20LEARNING%20REPORT_0.pdf

11 <https://www.lifechangestrust.org.uk/dementia-friendly-communities-evidence-and-learning>

12 <https://www.worcester.ac.uk/about/academic-schools/school-of-allied-health-and-community/allied-health-research/association-for-dementia-studies/ads-research/uk-meeting-centres.aspx>

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