STEPPING OUT OF ISOLATION TOGETHER

2021

ANNUAL REVIEW

DEMENTIA
CARERS COUNT
Supporting Family Carers

Welcome
from the Chair of the Board of Trustees

It is a privilege to be writing this, my first introduction to Dementia Carers Count's third Annual Review, as I step up to lead the Board of Trustees. I take over from Amanda Houlihan, who has led the Board since 2018 and who was a trustee of the organisation from 2010. Her tenure saw the charity through an incredible journey, and we all thank her for her commitment and hard work over the years.

I joined the Board of Trustees in 2019 and am incredibly proud to be part of this charity. We have a great team of staff and a strong Board, and it is this, combined with our ambition and our ability to think on our feet, adapt, and listen that has seen us go from strength to strength.

Charities play a vital role within the network of public services, and I am looking forward to leading this particular one through what continues to be an incredibly challenging time for our beneficiaries and the charity sector. We know that if we keep the needs of our beneficiaries, family carers of people with dementia, at the front and centre of our thoughts, this will be the key to our future success. Indeed, it is our partnership work with carers and critical input from our Carers Advisory Panel that enabled us to stay on the pulse of what carers needed throughout the pandemic, empowering us to develop our services accordingly. Since the last annual review, in response to what carers were telling us they needed, we have invested in developing our Virtual Carers Centre, which is now an accessible, nurturing virtual space for carers, no matter where they live in the UK.

In this review, we share stories from carers who we have helped support; we celebrate the success of Every Small Step 2020 and talk about our new and innovative service offers. Our theme this year has been 'stepping out of isolation together'. We are acutely aware that carers feel isolated at the best of times, and this past year has only amplified that.

At DCC we want a brighter, less isolated future for carers of people with dementia, and through events like Every Small Step we aim to raise awareness and vital funds for DCC to continue our important work.

Earlier this year we learned that unfortunately our Chief Executive Officer, Claire Goodchild would need to take long term sick leave to undergo treatment for a serious illness. We stay closely in touch with Claire, and she keeps us updated. Former Director of Communications and Marketing, Melanie Blanksby has returned to us as Acting CEO and we welcome her back on the team.

I am honoured to be part of the Board of Trustees. I would like to thank departing trustee Lee Marple for his contribution to the Board over a number of years, and warmly welcome our three new trustees: Gaynor Hillier, Darren Humphreys, and Haider Husain. I give thanks to the Board, staff, our Carers Advisory Panel, DCC Ambassadors, and of course all our supporters and carers. There is no doubt that we have challenging times ahead but, together, we can face the future with confidence.

Catherine A'Bear
Chair of the Board of Trustees

About Dementia Carers Count

We are a national charity which has worked to reach unmet health needs for 159 years.

We began as the Surgical Aid Society in 1862, and granted the ‘royal’ title in 1912, becoming the Royal Surgical Aid Society. At our 150th anniversary the Board agreed that we should focus on supporting family carers of people with dementia. Our new name was chosen to reflect our renewed mission and purpose, and Dementia Carers Count was officially launched in 2018.

Dementia Carers Count (DCC) offers a unique range of professional health and care support to the 700,000 family members and friends in the UK who are looking after someone with dementia.

At DCC we believe that dementia carers count, and we provide life-changing support that families living with dementia so often find isn’t there for them. We deliver free services - both face-to-face and online – that allow family carers to learn about dementia, to connect with others in a similar situation and to find ways to improve and maintain their own wellbeing while navigating the highs and lows of caring for someone with dementia. Everything we do is developed closely with family carers and delivered by professionals, so we can offer services that genuinely help carers with their needs.

Along with the rest of the world, over the last 18 months, DCC has had to change the way we support family dementia carers. We have taken the opportunity to develop new virtual sessions and digital support, to reach as many family carers as we can. Having pioneered these services during the pandemic we will continue to run and develop online support and content into the future, alongside other new and innovative services that meet the needs of carers wherever they may live.

✓ **DCC supports family, friends and partners in the UK who are looking after someone with Dementia.**

✓ **We are a national charity, for all carers, no matter where they live.**

✓ **We offer life-changing services for carers, all of which are based on strong evidence from our research.**

✓ **We aim to support 5000 carers over the coming year.**

Ruby's story

For several years before my mother's diagnosis it was clear that there was something wrong. It happened over a long period and the little things started to build up.

My mum was eventually diagnosed with Alzheimer's and vascular dementia in 2015.

There were signs that something wasn't right for about five years before that, for example her not being able to use the vacuum cleaner or not being interested in reading anymore. I tried to tell my siblings that there was a problem, but I think they were in denial. Even though I had seen the signs, when the diagnosis finally came, it was a shock.

I've always been close to my mum. Our relationship has improved as I've got older, and I supported her in many ways before she was diagnosed. While our relationship has kept steady, the diagnosis has added stress to other relationships within my family. I think that often happens. Adding a stressor like a dementia diagnosis to a family can cause some relationships to fracture.

Mum's dementia has progressed a lot in the last six years. She's been living with me during the pandemic, and she needs someone to be with her all the time now. She can't hold a conversation anymore, and her mobility has greatly reduced. She used to love watching Indian dramas, but she started to think the people were coming out of the TV, so these days we stick to nature programmes. It's very difficult watching someone you love unravel daily, but I'm also very grateful that I can help her.

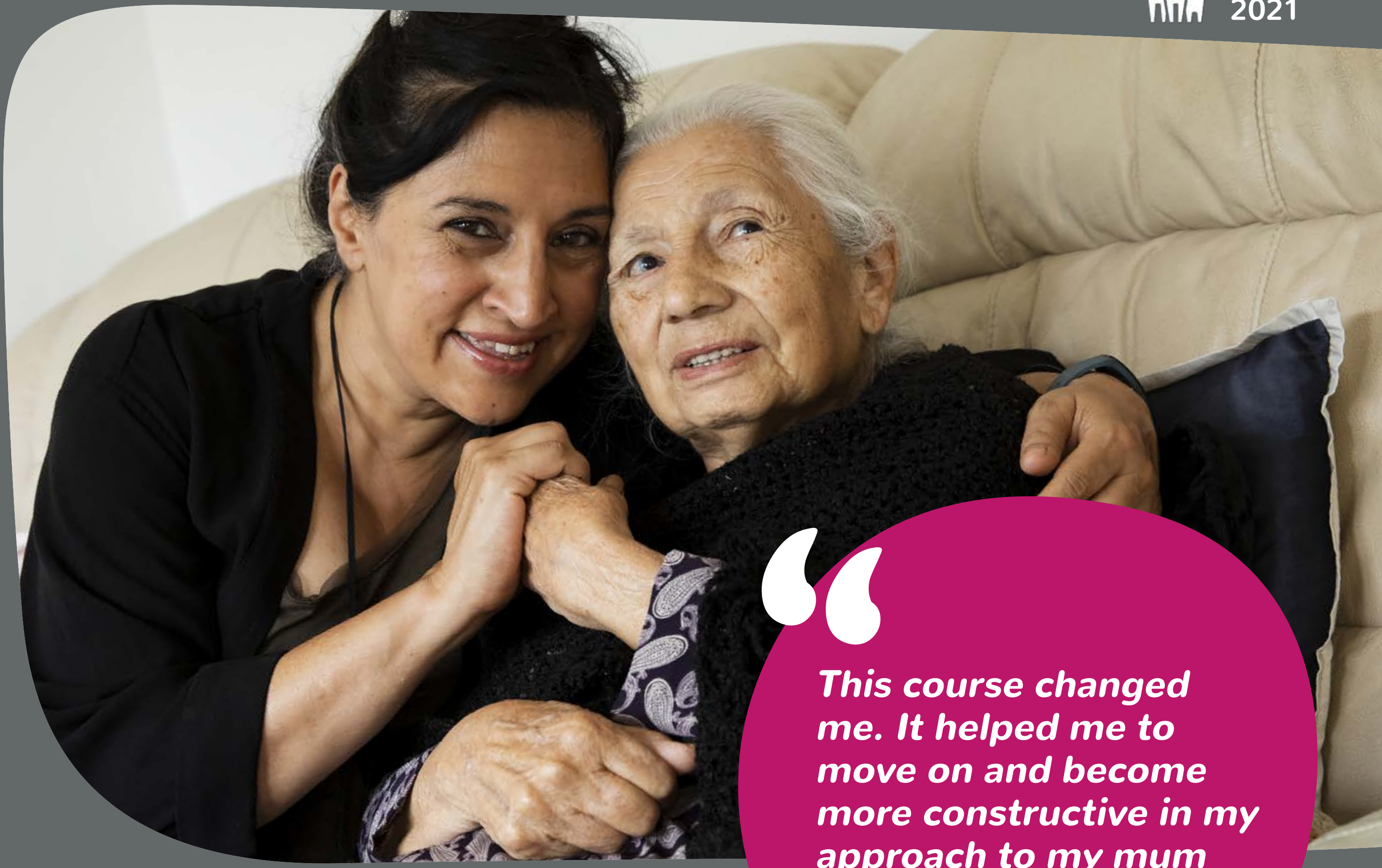
My brother lives with us too. He does the lion's share of the care, so I'm still able to work, but my days are very full. On the days that I'm doing mum's care, I get up early to meditate and set myself up for the day. Once mum is up, there isn't a moment for anything else until she goes to bed again. At about 6 pm, she starts to get out of sorts, I think it's tiredness and pain. On the days I'm working, I wake mum up to do her morning care. I start working later in the day and work into the night. I'm lucky to have that flexibility, but it is exhausting. I can't imagine how people in their 60s and 70s cope caring 24/7 without a break.

I don't get any support from medical or social services. It was almost as if their duty of care ended with her diagnosis; they gave us a name for what was happening but nothing else. I get emotional support from my friends and being able to talk about everything is a great relief. I've kept in touch with Dementia Carers Count since I went on their three-day course, and that has kept me going.

The pandemic has affected my mum. I've been very strict about people seeing her because she's vulnerable. She hasn't been going out as much or seeing anyone other than our bubble of four. She's had her jab now, and as summer comes, she's seeing people outdoors, but the winter was hard on her. I've also found lockdown tough. I was mentally and physically exhausted, and that's just starting to lift. I've kept my head above water by meditating and stretching, but sometimes I'm too tired even for that. When you're around the person you're caring for all the time, it's hard to process the emotional impact. You put all your feelings on the backburner, so you can focus on supporting the person who needs you, and that takes its toll.

Before I attended the three-day course, I felt nervous. At the time, I was in a very emotional place and knew that it might be difficult, but I was looking forward to meeting people who shared a similar experience. I also thought it was an amazing opportunity. When you're caring for someone with dementia, the focus is very often on them, but this was something just for me. I hadn't come across anything like it before, and I desperately needed it.

> ***"DCC's course is the first thing that felt like real support"***



> **This course changed me. It helped me to move on and become more constructive in my approach to my mum**

DCC's course is the first thing that felt like real support. It was clear a lot of effort had gone into organising and designing it, but the course leaders delivered it seamlessly. You felt like you were being looked after throughout and given space to rest and learn. Being around people who knew what you were going through felt hugely supportive. It's hard for people to understand what it's like to care for someone with dementia unless they've been through it.

This course changed me. Before, I was stuck responding reactively and ruled by my emotions. It helped me to move on and become more constructive in my approach to my mum.

The whole course was incredibly useful but learning what happens to someone when they have dementia was a lightbulb moment for me. That knowledge has made me feel more able to manage challenges with my mum. I take self-care much more seriously now. I realised that I need to take care of myself to be a good carer. I had always meditated but never thought of it as a tool for coping before. The whole course felt very caring.

During the three days, I bonded with the others on the course. It was a diverse group, and we brought with us a range of experiences. I was interested in hearing those experiences and learning from them.

I still refer to the materials from the course, and I visit the website a lot too. I find the Virtual Carers Centre especially valuable - the written information but also the videos and podcasts. As I've gone through different stages, I've accessed different types of resources, and it's been a great support.

Up until I attended the course, caring was a very lonely experience for me. Even though I have siblings and we all do our bit, it felt like we were working in silos. After going on the course and listening to other people, I realised there was support out there for me. For the first time, I felt like I wasn't alone, and that feeling was incredible.

Dementia Carers Count's 'Virtual Carers Centre'

Here to support you, wherever you are

The past year has transformed nearly every aspect of our world, including the way we now connect with each other and access support services.

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Dementia Carers Count has responded quickly by developing a range of first-class remote and online services that can be accessed within our Virtual Carers Centre (VCC). This means anyone can access professionally developed content 24 hours a day, seven days a week.

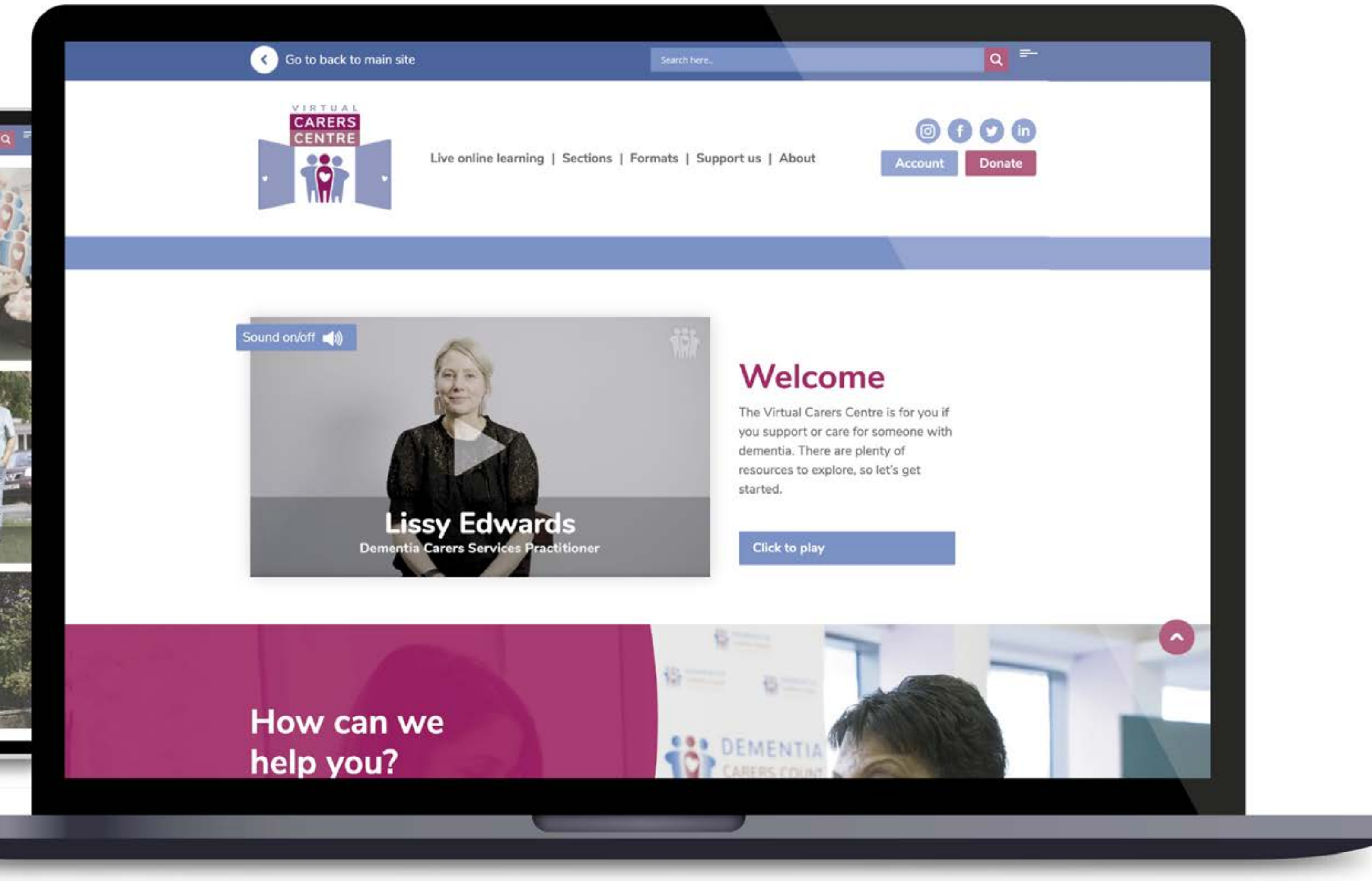
The VCC enables us to reach, support and connect more carers

Dementia is not just the brain getting older. It is caused by damage to the brain that can produce unpredictable results and symptoms that will be familiar to other carers.

At DCC we learn from carers about their needs and experiences to ensure this insight informs our future service development. We work closely with carers and partner organisations to build and refine a comprehensive programme of Live Online Learning sessions, and the VCC is where carers can register for them.

- **Access** a programme of 21 Live Online Learning sessions and on demand learning materials, delivered by professionals through a high-quality web platform
- **Register** for our learning sessions using a simple booking system
- **Read** articles
- **Listen** to podcasts
- **Watch** webinars, animations, and videos
- **Share** and interact on our carers' forum

The VCC also offers a range of opportunities for carers and supporters to become more involved with us through fundraising, campaigns, and becoming Ambassadors.



Welcome

The Virtual Carers Centre is for you if you support or care for someone with dementia. There are plenty of resources to explore, so let's get started.

How can we help you?

Mission, vision and objectives

Dementia Carers Count offers a unique range of professional health and care support to the 700,000 family members and friends in the UK who are looking after someone with dementia.

Strategic priorities for 2021-2024

1

Significantly increasing carer reach and inclusivity

- Bringing forward our reach targets from 2024 to demonstrate delivery of our charitable purpose
- Using evidence-based services to inform the organisation and drive its USP, including research to inform our EDI (Equity, Diversity and Inclusion) strategy

2

Moving to financial sustainability sooner

- Focusing on increased income generation, managed operating costs, and best investment return
- Delivering sustainable small financial surpluses that allow the organisation to further its purpose

3

Achieving a stronger voice

- Investing in a Policy & Campaigns function to increase awareness about the challenges that family carers face; with government, the general public, and the third sector
- Cementing DCC's position as the expert in family dementia care

4

Investigating innovative new routes to market that will drive accelerated service reach and income

- Including partnerships and joint ventures, as well as marketing around these specific objectives

Our vision

To nurture a generation of family carers of people with dementia to feel confident, supported, and heard.

Our mission

We provide welcoming environments for family carers of people with dementia, inspiring them to learn and to connect with each other and empowering them to continue caring for others and for themselves. We invest in research to understand family carers' experiences, needs, and outcomes.

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Who we are:

Staff team, board and Carers Advisory Panel

Trustees:

Catherine A'Bear
(Chair from June 2021)

Amanda Houlihan
(June 2010 – June 2021)

Tony Burch

William Burnand

Alan Cogbill

Richard Drummond

Julie Flower

Darren Garner

David Goodridge

Lee Marple
(March 2012 - June 2021)

Gaynor Hillier
(June 2021)

Darren Humphreys
(June 2021)

Haider Husain
(June 2021)

In June 2021 we welcomed three new board members and gave a big thanks to Amanda Houlihan, who has served as Chair since 2018 and as a trustee since 2010.

We are also thankful to Lee Marple who stepped down in 2021 having been a member of the Board of Trustees since 2012.

Senior leadership team:

Claire Goodchild
Chief Executive Officer

Melanie Blanksby
Acting Chief Executive Officer from June 2021

John Misselbrook
Director of Finance until March 2021

David Warren
Interim Director of Finance February 2021

Steve Dubbins
Director of Services

Lara Cooper
Director of Communications & Marketing

Mankit Yau
Director of Development

Tracey Williamson
Professor of Family Care in Dementia
(October 2018 – June 2021)

Carers Advisory Panel (CAP):

The members of our Carers Advisory Panel advise and guide us on our strategy and operational development. As current or former carers, they offer us real-life experience and perspective so that we can fine-tune our services to ensure we offer the best possible services to carers of people with dementia.

Jayne Goodrick
Manjit Nijjar
Peter Watson
Chris Roberts (honorary member)
Ming Ho
Trevor Salomon
Jill Davidson
Lara Dowd

Carers stats and facts

Unpaid carers

Since the beginning of the COVID-19 pandemic there has been a lot of research into the effects and impact of the crisis on unpaid carers, including some studies related specifically to carers of people with dementia.

there are 700,000 unpaid carers of people with dementia in the UK

There were up to

9.1m

unpaid carers across the UK before the COVID-19 pandemic, providing everything from a few hours of support a week to intensive and complex round the clock care

The pandemic has resulted in millions of new carers

4.5m

new to caring since the start of the pandemic

2.8m

of whom are juggling work and care

4 out of 5 unpaid carers

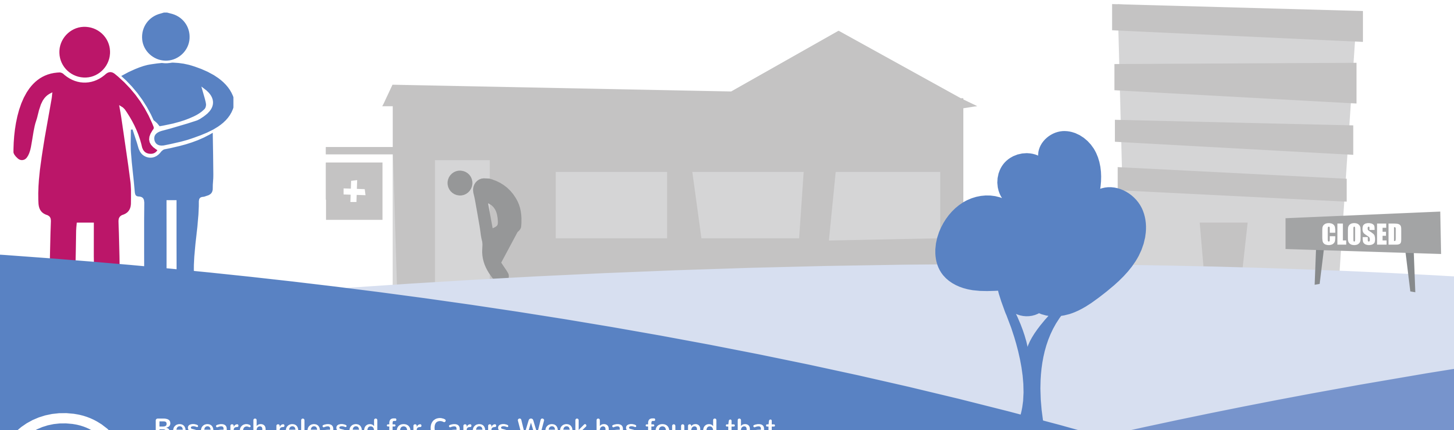
81% are currently providing more care than before lockdown

78% of carers report increased needs of the person they care for

64% said their mental health has worsened

58% of carers have seen their physical health impacted by caring

38% of carers are providing more care because of local services reducing or closing



Research released for Carers Week has found that carers **lost**, on average, **25 hours of support** a month they previously had from services or family and friends before the pandemic.

Carers are feeling exhausted and worn out from caring during the COVID-19 pandemic.

74%
of carers are exhausted from caring during the pandemic

72%
of carers have not had any breaks from their caring role

Of those who got a break:

33%
used the time to complete practical tasks or housework

26%
attended their medical appointments

Carers of those with dementia

People living with dementia were not prioritised for grocery deliveries during the pandemic which meant their carers had to deal with the practicalities of accessing food.

Many unpaid carers of people with dementia decided to stop paid carers entering the home due to the risk of infection. This meant unpaid carers had to increase their care hours.

Carers felt concerned by the risk of paid carers bringing coronavirus into the home. Lack of personal protective equipment (PPE) and feeling unprepared to provide additional care heightened these fears: “I didn’t know how to use all the equipment, and I didn’t feel safe and also didn’t know how to protect myself from injury as well as being a risk to Mum”.

Carers had difficult choices to make. Many avoided hospitals and other health providers. They struggled to weigh up the options of cancelling or continuing paid care and some described real fears of re-obtaining paid care post-COVID if they cancelled during lockdown: “A family friend of ours has already been told by their social worker that because they’ve managed without the [paid] care they’re not likely to get it back after the coronavirus”.

Implications for unpaid carers included increased workload and difficulty in accessing food deliveries: “At the moment I can’t get an online shopping slot. Trying to get through to the helpline to get us to be put on the vulnerable list has proved an impossibility, I’ve spent hours and hours and hours on the phone which gives you a layer of angst that on top of everything else you don’t need”.

Sources:

Carers UK | Caring behind closed doors: six months on | October 2020
Carers Week | Breaks or breakdown | 2021 report
NIHR | Informal dementia carers had to make difficult decisions about paid care during COVID-19 | January 2021

The expansion of our digital services in 2020

By Sue Hinds, Head of Services

Q **What were your biggest concerns when lockdown was announced in March 2020?**

A We had a three-day residential course booked at the start of lockdown with 19 people due to attend. This course, along with four three-day and two one-day courses had to be cancelled, impacting 80 people in total. Like all other services, we were unable to advise carers when we would be able to reschedule.

Carers book onto our courses for knowledge, help, and to develop ways to cope when caring for a person with dementia. Suddenly we faced great challenges in delivering something which would be of value to them. In the early stages of lockdown, we knew that, as well as our service being withdrawn, local services such as memory cafes, day centres, respite care and home care were also likely to be withdrawn alongside reductions (if any) of contact with family and friends.

The implication was that carers would experience feelings of isolation, have an increased carer burden, and perhaps have challenges in explaining what is happening to the person with dementia. We knew that this could also potentially result in them experiencing a range of reactions from the person they care for, as routines change and stimulating activities became limited. These concerns were later identified through our survey of carers in May 2020.

Additionally, we had assigned some places on these courses to newly recruited associate practitioners as part of their induction to provide the opportunity for them to observe and understand the approaches we use and the design of the courses. Whilst they are highly skilled professionals, we value giving them this opportunity and feel it prepares them well for their role within our team. We were also concerned for our current staff at DCC - working from home, unable to go out and 'do their stuff' with carers which they feel so passionate about and truly invest their energy in. So, we had to consider how to ensure their work with DCC was rewarding and engaging.

Primarily, we knew we needed to support the carers whose courses were cancelled. We decided to offer each person a support call, with the offer of talking through any challenges and providing emotional support if needed. As the lockdown continued, families were having to cope on their own with no outside support.

We then extended this offer to all carers who had previously attended any of our courses. We also offered individual coaching via Zoom or on the phone for those who faced specific challenges and who benefitted from some help discovering new ways of doing things or to reassure themselves that they were in fact doing the very best they could in extremely difficult situations.

306
attendances of our bespoke online learning package

Q **How did you decide what to do next?**

A It became clear that face-to-face courses would not resume for months, so we started to plan the development of online support and information.

To understand the challenges that carers were facing and what online information they would find helpful, we sent out surveys to carers via our social media channels. We received responses from 80 carers telling us that connection with others was important as they were feeling isolated and unsupported. Carers wanted information and advice about understanding and managing different aspects of dementia and useful strategies as well as ideas about how to explain COVID-19 restrictions effectively.

New articles, blogs, and videos were created by practitioners, carers, and Ambassadors. On the 13 May 2020 we launched our Virtual Carers Centre (VCC) - a hub of information and resources for carers covering subjects such as building resilience, managing everyday challenges, bitesize learning, resources for support during COVID-19 and so on.

In the first four weeks after launch, we saw a 102% increase in traffic to the DCC website and a 105% increase in new visitors. The engagement was brilliant, and the need was evident.

During this period, we were also approached by two external organisations seeking help to support their members deal with the feelings of isolation and the challenges that we had also identified in our survey. From July to September, we trialled bespoke Live Online Learning sessions for these organisations and the feedback was overwhelmingly positive.

It was important to us to create our courses in an online format that still provided an opportunity for carers to connect and receive information that resonated with real-life challenges. Our priority was to meet these needs in a dynamic, thought-provoking, and supportive forum. During the lockdown, we converted a refresher course into a four-week programme to welcome back and top up the knowledge and support for people. This also allowed us to test the use of group coaching in online sessions and our small group helped us to learn huge amounts about what works well and what the challenges are.

We also needed to balance these new, exciting, and positive approaches to our practice with keeping our eye on face-to-face courses. This created a whole logistical set of challenges about how to bring people together safely; time was spent scouring all the evidence, guidance and risks associated with coming back to in-person coaching so that we could do this safely by following all public health guidance. We were able to run four face-to-face, three-day courses in September and October 2020 and then looked to further develop online services as the country was locked down again.

After the successful pilot of Live Online Learning sessions during the summer, we launched them officially for all carers in November 2020 starting with six topics. We now offer 21 topics as part of a rolling programme. Sessions are kept small to encourage carer interaction, connection, and reflection. We have also created opportunities to engage in two longer courses that cover broader topic areas spread across four weeks.

Here is what some of our carers say about Live Online Sessions:

> ***"It made me feel that I wasn't alone, there are lots of echoes from people's experiences, pieces of the puzzle beginning to drop"***
>
> ***"It's really comforting to know that there's that help there and I can access it when I need to"***
>
> ***"After 17 years of caring I am looking for very specific things. DCC satisfy everything so far"***
>
> ***"I suddenly felt part of this group who were doing the same thing and doing their best"***
>
> ***"Brilliant bite-sized information pitched at a perfect, non-patronizing level"***

Q **How do you continue to offer support to carers?**

A We are currently supporting carers through our Live Online Learning (LOL) sessions, which last approximately 90 minutes and provide the opportunity to learn and connect with others in a safe space, where feelings and opinions are valued and supported. Our VCC remains available 24 hours a day and has a range of items on various topics carers have informed us that they would like to know about. We are also offering tailored packages to groups of people, sometimes brought together within a local community or workplace and through various organisations to supplement their work with our unique offers and skills.

Our team continually engages with carers and our Carers Advisory Panel, ensuring that we deliver timely and relevant services. We continually expand both our portfolio of topics, as well as the skills within the team.

We plan to create a service that combines face-to-face and digital offers to support as many carers as possible and to always listen, evaluate, and adapt so that we can support them in the very best way we can.

504
attendances of our Live Online Learning sessions

THE
LINBURY
TRUST

Q **Looking forward, how do you see the future development of DCC's carer support services?**

A Thanks to the Linbury Trust for a multi-year grant, which helps facilitate the development of our exciting platform for the VCC, we continue to bring together all our resources and learning opportunities in a dynamic, user-friendly virtual space.

Furthermore, we work with several partner organisations creating bespoke packages to not only respond to local populations' needs but also allow carers to connect with people within their geographical region or workplace. This will hopefully facilitate them to keep in touch and support each other - making meeting together easier. Our support services will continue to evolve: every aspect of what we have now serves a tremendous function and we want to keep our services responsive and world-class.

We will return to face-to-face courses as soon as it is safe to do so. We are excited about developing a range of different courses/workshops across the UK that can support carers who are unable to travel or want to learn in different ways. We are therefore working towards developing an assortment of services that are as inclusive and accessible as possible for all. Join us on our journey.

> ***“Amazing, so many things have fallen into place and now enable me to make sense of mum's behaviour”***

Every Small Step

In October 2020, DCC produced its first-ever virtual and online event.

In previous years we had run an annual conference in the autumn, but we took the view in Spring 2020 that COVID-19 would require a change in thinking. At that time, it seemed that restrictions might be lifted by the autumn. However, even if this were to be the case, we felt that people might not feel comfortable attending a face-to-face event for many reasons. As a result, we took this challenge as an opportunity to develop something we might never otherwise have tried.

By thinking more broadly, not only would we be able to hold an event during a possible lockdown situation, but we would also have the potential to engage a wider, different, and larger audience. It was a chance to try a new and innovative approach. We wanted to reach family carers as well as the wider sector and influencers, and to bring potential donors and funders into the fold.

Working with agency Run2Events we developed a five day ‘challenge event’, which encompassed a walking challenge alongside the production of new and interesting content for participants to engage with. The goal was to reach a cumulative total of 700,000 steps during the event – one for every family dementia carer in the UK.

Tying in with 2020’s organisational theme of building community and working together, ‘Every Small Step’ was born. Six podcasts were recorded for the event: each being a conversation between two people about a particular aspect of caring for someone with dementia. Guests included DCC’s Carers Advisory Panel members, DCC course alumni and Ambassadors, and well-known personalities. The conversations were diverse, covering the highs and the lows of caring, often raising smiles, tears, and hope all at once. On each day of the event, a new podcast was available for participants to download and listen to on a daily walk.

We were able to engage actor Shobna Gulati to officially support Every Small Step, including recording a podcast for us. Shobna lost her mother to dementia and published a book about her experience in September 2020. We also recorded video messages of support from public figures, actors, podcasters and carers, and celebrities who were engaged to share our social media posts.

Not only did we go well beyond our step target in totalling over 2 million steps, but also, without making Every Small Step explicitly a fundraising event, we raised over £9,000 in donations. The event was very well-received both internally and externally.

Every
Small
Step

Sarah’s story

I wasn’t always my dad’s primary carer, but the year after he was diagnosed with Alzheimer’s, my mum passed away. After that, I started coming home from uni every weekend to do his shopping and cleaning. Once I finished my degree, I knew I had to move back to be close to him, otherwise commuting and caring would be too much.

My dad was diagnosed with young-onset Alzheimer’s six years ago.

Before then, he was a bit forgetful but not in a way that was worrying to us. When my mum first told me he had Alzheimer’s, the impact of the diagnosis didn’t really sink in. I was living away from home and attending university in Newcastle. I supported my mum while she cared for dad, but she was the primary caregiver, and I think she protected us from it. We never spoke about how it made her feel, but after she died, I found some information she had on counselling services, and I realised how hard it must have been for her.

I decided to become an occupational therapist because I knew I could get a job anywhere in the world once I qualified. I’ve always wanted to travel, but I can’t now. I’ve made all my career decisions so I can fit my dad’s care around work. When I first started working, I was doing nights because that was the only way I could take my dad to his appointments during the day. Bringing someone to the doctor is impossible when you’re working nine to five.

I’m in my early thirties and feel like I’m at a completely different life stage from my friends. They’re getting married and starting families, and I’m stuck here. I do socialise, but it’s hard to fit everything in. I work full-time, and there’s always something to do for dad. Even though I work in a crisis team for the NHS, caring for my dad is the hardest job I’ve ever had.

I have mixed emotions about being a carer. A part of me resents it, but it also makes me really happy. I’m able to make my dad feel safe and secure in a world that doesn’t make much sense to him, and I’m grateful that I can do that. Caring for him has changed our relationship. Growing up, I was a bit of a daddy’s girl but never as close to him as my mum. Now I see how similar we are.

For the most part, the pandemic hasn’t affected my father, but it’s had an impact on his family and friends. During the first lockdown - in an attempt to keep my dad safe - my brothers stopped visiting, and I kept it up alone.

I wondered if I should keep seeing him because I was still going to work every day, but if I didn’t go, the shopping or washing wouldn’t get done. I didn’t feel I had much choice. As the pandemic has gone on, we’ve found a way of making it work and my brothers and I take turns visiting. My dad’s best friend has been shielding this past year, and I know he’s worried my dad won’t remember him when they see each other again.

I don’t get much support from social services. Anytime I’ve tried it’s ended up being more stressful than if I just did the care myself. Someone comes three times a week to check dad is taking his medication, and I’d like more help so that when I come, there isn’t so much to do. It’s hard to find the right people who understand his personality and what he needs and the time to organise it all.

> “*My experience with DCC has made me a better carer for my dad*”

In five years of caring for my father, DCC's three-day course is the best thing I've come across.

It came to me at a time when I was struggling, and it was like hitting a reset button. I did feel a bit nervous before the course. I wasn't sure what to expect, especially because I attended during Covid, but that wasn't an issue, and I felt completely safe and cared for the whole time. I was excited too. When I attended the Dementia Carers Count course, it was the first time I sat in a room with other carers.

I thought that this could be the place where I finally get some support and a bit of respite. After the first few hours, I was completely comfortable, and everyone was so welcoming. The course itself was a bit of a rollercoaster of emotions. It was amazing to chat to people, hear about their situations and relate them to my own - that shared experience was a highlight. Sharing my problems with people in a similar situation, who understood what I was experiencing during the group coaching session, was particularly helpful. It felt like a very safe and supportive environment.

In the evenings, you had time to process it all and think about things more deeply. That's not an opportunity you often get when you're caring for someone else all the time.

It felt like the course leaders cared about us and were interested in what we had to say. You could see they had a wealth of knowledge and wanted to help us - I wished I had one of them in my pocket to keep me going. After the course, I sorted out a lot of practical things, like my dad's council tax benefit and attendance allowance, that I had been putting off. It was the boost I needed to get things done.

My experience with DCC has made me a better carer for my dad. Our communication has improved, and I have the patience to deal with challenging situations now that I understand the reason behind his behaviour.

I found it helpful to learn about personality and how that comes into play - both for myself and my dad. It's easy to get dragged into thinking that everything is about Alzheimer's and lose sight of the person they are. The course also made me think about my resilience and how important it is to look after myself. On my fridge, I've put a list of things I can do to relax. Some take five minutes, and some are a bit longer, but it's a good reminder to check in with myself.

I would recommend the course to anyone. Even if you attend and don't contribute much, you'll still benefit just from talking to the other people there. Give it a go because you're missing out if you don't.

Community engagement and fundraising

How to engage the public when you're stuck at home?

Our community engagement officer Yael has certainly not been stuck, she has been joining various groups for their meetings on Zoom, from London to Sheffield to Cumbria. Zoom makes the UK a much smaller place, and she's happy she can do it all while in her slippers.

The benefits of speaking to people online are many, but something our engagement team has noticed is that participants tend to be less inhibited, attending from their sitting rooms, they feel comfortable asking questions, and they can go straight online after meeting with us have a look at our website, book on a DCC course or even donate. We have been privileged to join carers groups and see, first-hand, how they manage to attend a meeting on Zoom while simultaneously caring for someone with dementia. It has been a humbling and productive year, to say the least.

We have met with several different groups over the last year, including The Women's Institute groups who have been great hosts, welcoming us at their virtual meetings and reaching out to their members about everything DCC has to offer. DCC has also been part of an article in Lions Clubs magazine which reaches 1000s of members, and a conversation with the charity Jewish Care means more carers of people with dementia will hear about our work. We are looking forward to meeting many more groups over the coming months both virtually and in-person.

Giving in memory

Giving in memory of someone who has died can be a meaningful way of honouring them. We are proud partners of MuchLoved, a platform for online tribute pages. Setting up a page is easy, and a lovely way of sharing photos, messages and memories from friends and family wherever they live in the world.

Writing a Will can help give people peace of mind for the future, which is why DCC has teamed up with Farewill, the largest Will writer in the UK, which has won multiple awards for its service, including National Will Writing Firm of the Year 2019 & 2020 at the British Wills and Probate Awards.

With no obligation to leave a gift, supporters can now access DCC's free Will writing service.

What have our supporters been up to?

There are so many ways to raise money to support DCC's vital work and we have had some wonderful supporters this year – here are just a couple of them:

Sisters Millie and Jasmine are raising funds and awareness for us by skydiving. Their nan has dementia and they decided they wanted to do a little something outside the box to support DCC – we're not sure they quite imagined that box would be a plane at 10,000ft!

Mel and Kofi opted for a sponsored swim. Kofi is a full-time carer for his nan who lives with dementia and they decided to swim as Melissa is wheelchair-bound. In water she no longer has the restriction of gravity and no longer feels like she has a disability. There is no stopping these two – they even have an amazing employer, Aviva, who not only match what they raise, but DCC was also part of the Aviva Community Fund campaign in December and thanks to donations from other Aviva employees we received over £1,500.

This year we went out walking to raise money for carers.

Every Small Step

A word from our special guest and supporter, John Stiles

John Stiles is the son of the late football World Cup winner Nobby Stiles. Nobby died in October 2020 with advanced dementia. John, a former professional footballer, works as an after-dinner speaker and comedian, supports our work.

Q **Tell us about your dad. What was it like growing up with a World Cup winner?**

A Growing up, we didn't know how famous my dad was or what he had achieved by winning the World Cup. Football was never mentioned at home, and my dad was just my dad - he was the most humble, hard-working man you'll ever meet. When we went out as a family, that's when we knew how special he was. People treated me differently when they found out my father was Nobby Stiles.

Q **What happened to dad? How did your family respond to his diagnosis?**

A When he was 60, he had a heart attack, and not long after his memory started to get worse. It gradually progressed until he got to the point where he needed help to work. At the time, dad was an after-dinner speaker, and we started to work together. I'd memorised all his stories and knew when he went off track what I had to say to get him back on. For almost three years, he worked solely with me, and we had a special time together that we wouldn't have had otherwise.

In 2013 he had a huge dip, which seems to be common with footballers because of the trauma to the brain, and we never really got him back after that. It was 18 years of watching him slowly leave us, and it was particularly hard for my mum.

Q **Why have you chosen to support Dementia Carers Count?**

A There is very little out there in terms of support for the families of people with dementia. As a family, we didn't know where to turn when dad was diagnosed. Had we known about DCC, we'd have had access to support and knowledge, which would have helped us loads in caring for dad. I want to make sure every family going through what we went through knows about your work, and if I can help at all in raising awareness and the profile of DCC, I will.

As well as supporting DCC, John campaigns with charity, Head for Change, which works to create a safe space for sporting heroes, past, present, and future with sports-related brain injuries, supporting the people affected and campaigning for positive change through research and raising awareness.

There are countless ways people can support our work whether they are active or not. From bake sales, silent auctions, to running, cycling and everything else that's possible. Our fundraising team is here to help our supporters however we can. Contact fundraising@dementiacarers.org.uk for ideas and tips on fundraising.

Financial summary

Annual report and accounts

The Royal Surgical Aid Society

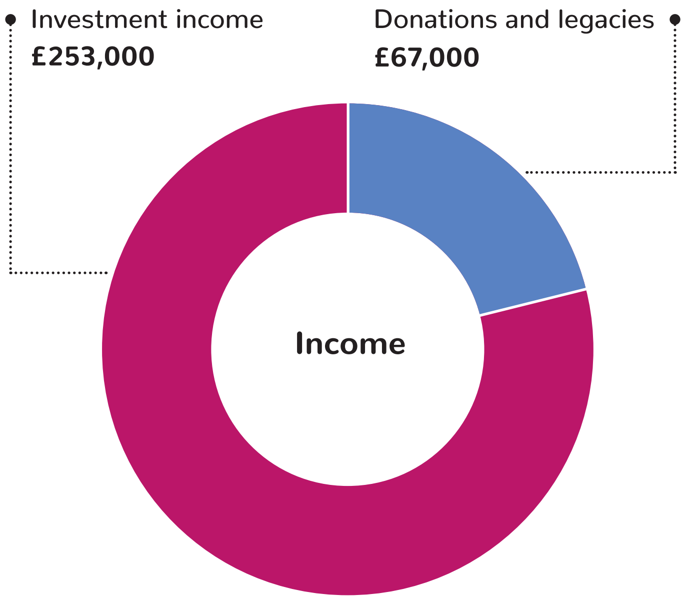
Statement of financial activities

(including income and Expenditure Account)

For the year ended 31 December 2020

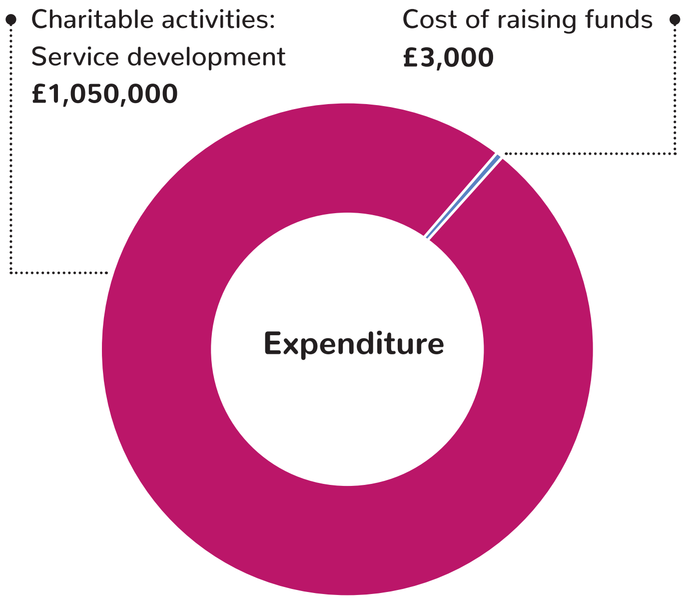
Total income

£320,000



Total expenditure

£1,045,000



Net operating expenditure

£725,000

Building on the development from prior periods, the net expenditure of £725k for the year to 31 December 2020 represents a continuing and significant investment in building and developing the service model and organisational infrastructure necessary for the future delivery of our mission.

The Royal Surgical Aid Society

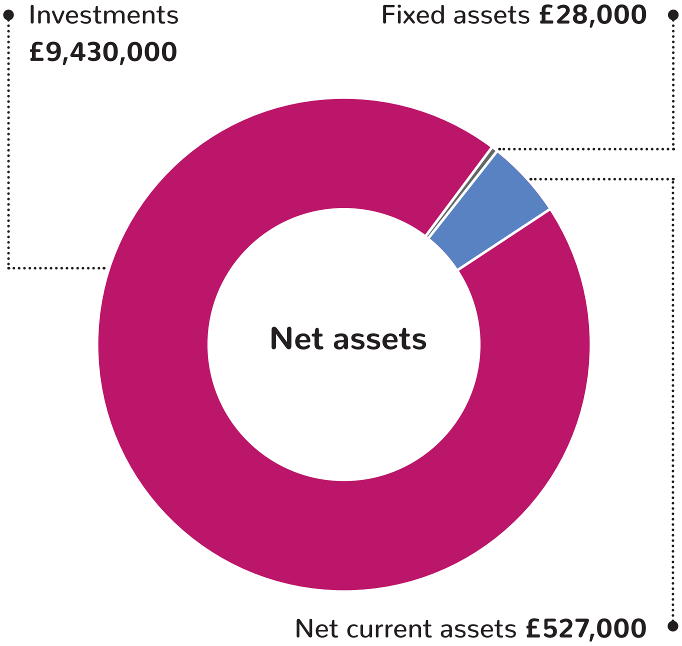
Balance sheet

As at 31 December 2020

Continuing to build on the planned strategic investment from earlier periods, the net expenditure of £725k for the year to 31 December 2020 represents a further and significant financial commitment in building and developing the service model and organisational infrastructure necessary for the future delivery of our mission.

Total net assets

£9,985,000



Funds

Unrestricted funds

Designated funds £9,098,000

General fund £887,000

Total funds

£9,985,000

The Trustees have previously committed a sizeable portion of DCC funds for capital investment in the DCC National Centre with an element of the cost generated through capital fundraising. The strategy for a National Centre is currently being reviewed in light of the shift towards online learning brought about by the pandemic.

All remaining reserves will be utilised in the continued development of a sustainable model, following which residual funds, together with income from service delivery and operational fundraising, will be at a level sufficient for the ongoing delivery of our objectives.

Stuart's story

I met Roger in 1985 and we've been in a registered partnership since 1995. He's 12 years younger than me and, rather naively, I thought he'd be the one looking after me in my old age. Roger is from Norway, and we lived there together for about 30 years, but our social life was slowly ebbing away, and I felt my family could offer more support than our friends in Oslo, so in February 2020 we moved to the UK.

Roger was diagnosed with young-onset Alzheimer's when he was 57, four years ago.

My background is in nursing - general nursing, intensive care, heart surgery patients and later, nursing in the community. I had some contact with people with dementia, but nothing could have prepared me for young-onset Alzheimer's. I had never experienced anyone with apraxia, and that's one of the biggest challenges for me. It's not something I expected to happen with dementia.

Roger was always good at the practical jobs around the house. He was in charge of fixing things, and I just left him to it. Now that's become my responsibility and as well as caring for him full-time, it's a lot to learn. Roger has deteriorated considerably since the diagnosis. He's lost some of his verbal communication. I speak fluent Norwegian, and he still understands English but even in his mother tongue, it's hard to get answers out of him. He doesn't enjoy the same things he used to, even something simple like sitting in the sun, he doesn't have any interest in now. Luckily, his mood has remained good. He's always smiling, and people tend to be drawn to him.

Gradually, I've taken on more and more. Roger can't go for walks without me, and I prepare all his food. When he was first diagnosed, I wanted to let him do as much as possible for himself. I get a bit frustrated now that I'm slowly having to do more and more for him, and I resent it a bit. I didn't choose to be a carer and thought that by now, I would be enjoying my retirement and living happily ever after. Like many gay couples, we don't have children, and I wonder if that's made it more difficult to be a carer. People who have children have that experience of guiding and nurturing to fall back on if they go into a caring role later in life. If you've never had children, you don't have that.

When it's just you and the person you care for, you feel like you're almost in a capsule, cut off from the outside world. It can be very easy to think something is just a symptom of Alzheimer's and what you must put up with, rather than reaching out for support. The Dementia Carers Count (DCC) website has helped me with that. I read an article that said 'never be afraid to get help' because that's the bravest thing to do. Reading about other people's experiences has helped me process some of Roger's symptoms, and now I've made a doctor's appointment to discuss them and see if we can get additional support.

I began using technology more at the start of the pandemic. Zoom was a new thing, and I did struggle with it in the beginning. It's been a great reprieve during lockdown. Just having a normal conversation can be a luxury because I don't get to have that with the person I live with anymore. He's the same in many ways, but we've lost that communication. We always had conflicting viewpoints and would have hefty discussions about whatever was going on in the world, but that's changed quite a lot.

> ***"The online courses have been like gold dust and have increased my knowledge of dementia and Alzheimer's"***

I found out about Dementia Carers Count in an online young-onset support group. Someone there spoke about the support she'd received from the charity, and she was very knowledgeable. When I started attending DCC's Live Online Learning sessions, I realised why. The online courses have been like gold dust and have increased my knowledge of dementia and Alzheimer's. The people leading the sessions are so easy-going, supportive, and understanding. It feels like they are always on our side. They've been a lifeline for people like me during the pandemic.

I'm building a strong foundation of information and finding more ways to deal with the changes in Roger's behaviour. The session on psychological attachment was particularly fascinating. At the time, I didn't understand why Roger was following me around the house, but now I do. Instead of getting frustrated, I took it as a compliment because I know now that he feels safe with me.

DCC's Live Online Learning sessions are fantastic. They are very informative, accessible, and the content is presented in a way that is easy to understand. During the sessions, you can talk about your specific challenges and connect with the other people attending. Without DCC, I would be completely lacking in knowledge and information about dementia, despite my medical background.

The support DCC provides has helped me immensely and would be extremely useful to anyone in a caring situation. First and foremost because the information comes from people with experience and knowledge. It will help you understand what is going on for the person you care for and develop a better caring strategy. Everyone running the sessions is very patient and nurturing towards the people attending. If you need more information about dementia, and everyone in a caring role does, use DCC to get it.

> ***"DCC's Live Online Learning sessions are fantastic. They are very informative, accessible and the content is presented in a way that is easy to understand"***

A word from Melanie Blanksby
Acting Chief Executive Officer

Understanding and adapting to the changing needs of family carers of people with dementia has been at the heart of the work of ***our team of health and care professionals*** *over the last twelve months. They have been building on the foundations of the three-day and one-day courses, to bring additional resources to partners, husbands, wives, sons, daughters, in-laws, siblings, nieces and grandsons, friends and community leaders looking after someone with dementia.*

With the support of our Board, our whole organisation has worked to refresh our approach to focus on reaching as many of the 700, 000 families impacted by becoming unpaid carers of people with dementia.

Stepping out of isolation together and mindful that the months ahead may still not be easy to plan for, we have invested in our Virtual Carers Centre to give new ways to access advice and support from our team of health, care and legal professionals. Mindful that we all access information in different ways, we continue to build a range of accessible content including video, audio, useful downloadable information and our short 'live online' courses.

At the same time, we are now available to visit and work with communities and partners across the United Kingdom and already have new plans in place to deliver a range of face-to-face support with a growing number of practitioners and associates in a range of geographical locations including Scotland and Wales.

The support of our Carers Advisory Panel and trustees remains essential to bring rigour and challenge to our delivery, and to keep carers at the centre of everything that we do, and we thank them for their wisdom and counsel as we expand our services and reach out further to new beneficiaries.

Our Ambassadors will be increasingly important as we meet carers in their networks over the coming months and we look forward to developing our connections with those needing support both online and in person.

Our virtual doors are open wide to welcome new families, friends and community leaders to join Dementia Carers Count in the way which suits them best, and we also look forward to accepting invitations to meet groups of carers in different regions to talk about our work and deliver our services over the coming months.

Thank you for supporting us on **every small step** of our journey to improve the lives of those caring for and supporting someone with dementia.

Melanie Blanksby
Acting Chief Executive Officer,
Dementia Carers Count

Acknowledgements:

- Albert Hunt Trust
- Aviva
- Childwick Trust
- Donald Forrester Trust
- Linbury Trust
- McLay Dementia Trust
- MSD
- W E Dunn Trust
- The Grace Trust
- Barston Association
- Finchley Reform Synagogue
- Women's Institute
- Lions Clubs
- Jewish Care
- Bernard Piggott Charitable Trust

Thank You ♥

Photographs: Alexander Caminada Photography

Dementia Carers Count supports family, friends and partners looking after someone with dementia.

DEMENTIA
CARERS COUNT
Supporting Family Carers

To find out more please contact our team:

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@DemCarersCount
@DemCarersCount
@DementiaCarersCount
find us on LinkedIn

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Dementia Carers Count is the working name for The Royal Surgical Aid Society, registered charity in England and Wales: 216613