DEMENTIA
CARERS COUNT
Supporting Family Carers

2022
Annual Review

Foreword from the Chair of the Board of Trustees

**Catherine A'Bear,
Chair of the Board of Trustees**

Whenever I talk to family carers or read about their experiences it reinforces how important our work is.

Kelly, whose story is contained in this Review, reminds us that being a carer is a hidden role. It's our job at Dementia Carers Count (DCC) to shine a light on that hidden work, talk to family carers of people with dementia to understand what information and support they need, and then work out how best we can help. In 2021 we took stock of what we had learnt from our work to date, including trialling the delivery of some of our services online during the pandemic lockdowns, put together our plans for the next three years and continued to build our staff team to deliver those plans. We are incredibly grateful to the members of our Carers Advisory Panel and our Ambassadors for their thoughts and wisdom that assisted us in this process.

2021 was also a year of intense sadness for us. Our Chief Executive, Claire Goodchild, who had been so instrumental in transforming the Royal Surgical Aid Society into Dementia Carers Count, died after enduring a long period of ill health. We all mourn her passing. As Trustees, we have been very grateful to Melanie Blanksby, who stepped into the role of Acting CEO during the summer of 2021, and to the whole staff team, for making sure that we continue to put the needs of family carers at the front and centre of everything we do.

You will read in this Annual Review of our promise to support a generation of family carers of people with dementia to feel confident, supported, and heard. We are fulfilling this promise by taking action in four areas:

- increasing the reach of our services
- being a stronger voice for our family carers to government
- innovating to ensure the services we offer respond to the needs expressed to us by carers
- ensuring that we generate funds each year so that we can continue to deliver these services long into the future

You will find more information on the progress we are making within the following pages and you can read first-hand reports from some of our carers about how they have used our services.

It continues to be my privilege to work with my colleague Trustees and, this year, I pay particular tribute to three of them: Tony Burch, Darren Garner and Richard Drummond, who all complete their time on the Board in 2022. They have each played an important role during a period of great change for DCC and we thank them for their time and their considered and expert contributions. We are just finalising the recruitment of new board members at the time of writing, and this is an essential part of how we continue to renew and regenerate.

I will leave the last word to Keiko, Howard and Kelly who have all been kind enough to share their experiences about the value they all found in Dementia Carers Count helping them to focus on their own health and wellbeing. As Keiko says: "Dementia is part of our lives now and we're doing our best to carry on." At DCC we will also continue to do our best.

DEMENTIA
CARERS COUNT
Supporting Family Carers

Our Mission

To provide welcoming environments for family carers of people with dementia and inspire them to learn and connect with each other. To make sure they are empowered to continue caring for others and themselves. To invest in a programme of insight, alongside policy and campaigning work, that will help us to better understand and support family carers' experiences and needs.

Our Vision

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

Strategy

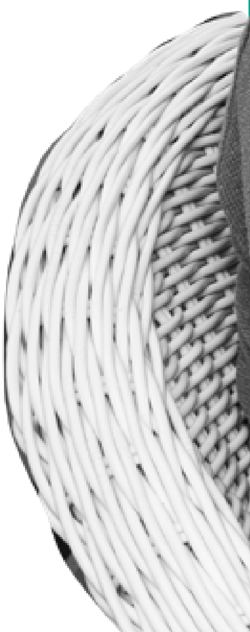
2022 marks the 160th anniversary of the Royal Surgical Aid Society. Historically, RSAS has always focused on unmet needs in society, and how best to bridge these gaps in provision. So, in 2015, the charity identified a need to support and empower family carers of people with dementia.

It was relaunched as Dementia Carers Count in 2018, offering innovative and high-quality services centred around the needs of family carers of people with dementia; equipping them to better cope with their caring role and to feel supported in the challenges they face daily.

One of DCC's central principles is to listen to and understand carers. Using ongoing insight, learning, evidence and the direct involvement of carers, we continually take stock, adapt and develop our offers. Through the challenges of the COVID-19 pandemic, DCC saw the importance of continuing to support carers and took the positive opportunity to quickly develop new formats and services that could still be made available during a lockdown situation. During and following the pandemic, there has also been a more general sea-change in the way that individuals behave and how they engage with organisations. DCC took this insight to develop a refreshed strategy for the charity.

Our strategy for 2021-2024 focuses on maximising DCC's reach to carers and on becoming financially sustainable for the future.

To reach as many carers as we can, a carefully considered blend of support – from face-to-face courses to online sessions and accessible resources and information - forms the current centrepiece of our services for carers, but we aim to scale and shift based on what we continue to learn about those who need our support. For example, in the second half of 2022, we have launched a 24-hour text service and a telephone line to enable each carer to access our services in a way that best suits them. Our new policy and campaigning function has created the opportunity to position DCC in the sector as the experts in family dementia care and a voice for carers. Our first survey of family dementia carers this summer brought in over 400 responses, giving us a wealth of information and insight into the experiences of carers. We continue to expand our work with partner organisations across the UK, understanding local needs and delivering our services through existing networks. Equality, Diversity and Inclusion have also been a key part of our work in 2022, helping to ensure that our services are accessible and that we are reaching out to those communities and groups that most need us.



To ensure that we can be there for carers in the long term, generating reliable sources of income for the organisation is essential. Our expanded Income Generation team focuses on several areas including fundraising from individuals, from communities, and from Trusts & Foundations; developing corporate partnerships; and driving income through providing paid-for services to commercial clients.

The more we can do for carers and the more that the wider public knows about what DCC does, the greater the potential we have to support as many people as possible.

Photo: Alexander Caminada

Keiko's story

I met Javed at college in 1974. I had come to the UK from Tokyo to study English, and he was doing a postgrad in banking. After a year, I went back to Japan and Javed proposed to me. I wanted him to move to Japan, but he couldn't speak the language and it was impossible for him to find work. So, four years after we first met I decided to move to London to be with him.

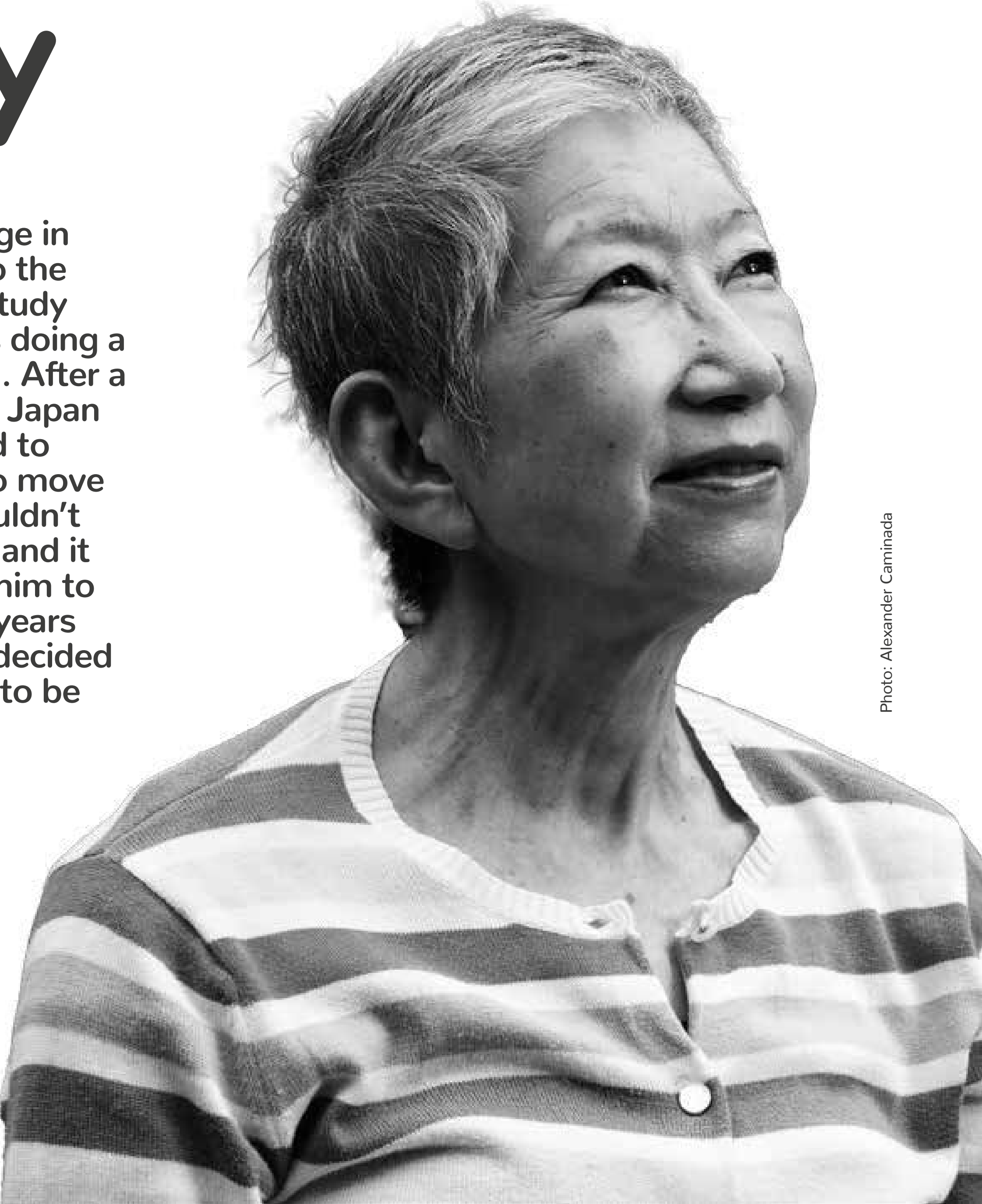
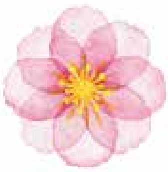


Photo: Alexander Caminada



Both our families objected to our marriage, but my parents eventually gave us their blessing and they attended our wedding in 1978. We settled in London, worked and did all the usual things. We have two children and they're both in their 30s now.

In 2017, I retired from my full-time job but started working part-time in a supermarket to keep myself occupied. Around this time, Javed went on a family trip to North Wales without me and when they came back his nephew said Javed had been acting strangely. My husband had always been chatty and social, but he was becoming more confined to himself. I thought it was just his usual forgetfulness but I contacted our GP for advice. It took some time before they decided to send Javed for a memory test, but then the pandemic started.

Nothing was moving because of the pandemic and our GP suggested we opt for private help. In November 2020 Javed was assessed for the first time. After that, our appointments kept getting cancelled. In March 2021 we went for another MRI. A report from a neurologist and a psychiatrist suggested Javed had dementia which might have been caused by sleep apnea.

Even after the diagnosis, I was very optimistic that Javed was just forgetful and that we could carry on as normal. At the time, Javed was working for the Metropolitan Police. He wanted to keep working but there was a restructure and his position closed. He was offered another job but it was too far to travel, so he decided to retire.

Javed's retirement coincided with the pandemic and that affected him a lot. Last summer he was able go out alone, but now he was starting to lose his keys and forget the pin code for his bank card. He even refused to visit his brother and sister and would hide when they came over. Around the same time, he became a bit aggressive towards me. Our GP assessed him, prescribed some new medication and he's become more stable.

Everything is more challenging now. We've lost some of our communication, so if Javed's mood changes, I wonder if it's something I've said or done. I know it doesn't help to blame myself and I just have to carry on. When Javed was diagnosed, I didn't want to believe it. It took time to come to terms with it, but this is a part of my life that I can't change.

I'm trying to find a day centre to get some respite and maintain my mental health. By the end of the day, I just want to go to sleep, and I still need to manage everything in the house. The only time I have for myself is when I'm at work. During the pandemic, I really struggled because nothing was open. I contacted social services and was referred to some local organisations, unfortunately, all activities and dementia clubs were suspended. I felt very lonely.

We've been to the memory lounge every Monday since it reopened. They organised a face-to-face DCC course for five weeks. It was wonderful. There were additional volunteer carers to look after the people with dementia while we attended the course. It was very helpful to be able to ask questions and share my experiences with professionals. Listening to the other participants gave me courage because now I know that I'm not alone. We all struggle sometimes.

Before I attended the five-week course, I did lots of Live Online Learning sessions with DCC.
At the start, I was very nervous because I didn't know anything about dementia, and I was already mentally exhausted. I even felt a bit scared about introducing myself. Once the session started, I felt comfortable and found I wanted to share a lot. I really appreciated listening to the other carers share their experiences.

The course leaders were always understanding, accommodating and professional. I felt very encouraged because a lot of services focus on the person with dementia, but DCC focuses on the carer. I understand now that to be able to care for Javed I need to be mentally and physically sound and healthy. As a carer looking after yourself is so important, and DCC helps you do that. The online sessions were great because I could keep my husband with me while participating, but I still got to meet people and share information.

"If you have the opportunity I think you should participate in everything you can. Don't lock yourself inside; try to come out and enjoy life. Dementia is part of our lives now and we're doing our best to carry on".

Q & A

Developing our offers

Opportunities, partnerships and development

Claire Reading

What are the development plans for Dementia Carers Count?

Throughout the pandemic, our plans had to change quickly to reflect a need for us to help more people remotely. As a result, the Board decided to invest in income generation through fundraising activity and business development, to become more sustainable through grants, individual giving, corporate engagement and other commercial activities. This will raise the money needed to help us to reach more carers.

Since I joined in March, I've been learning about DCC and the unique services we're delivering to family carers. This has helped build our plans and shape opportunities through joined-up initiatives that, not only help more family carers and engage with our volunteers and Ambassadors, but will ultimately extend our reach to new audiences.

We are already working with a number of partners, businesses and community groups to deliver staff and volunteer training, and we are developing this work further to establish new relationships and new income streams to create a pipeline for service delivery.

We're exploring several opportunities at the moment with our partners and focussing on strategic relationships that will help to promote DCC across commercial sectors. By creating targeted propositions and new engagement strategies, we will find new ways to reach more people.

Tell us a little bit more about some of the new initiatives to support carers

We know that most people caring for someone with dementia experience loneliness, and we want to ensure that people don't feel they have to cope on their own, which is why we have launched our new text service for dementia carers, to text when they may be struggling with anxiety, loneliness or depression.

The service is there 24/7 to help people work through their worries and signpost them to Dementia Carers Count resources and other support services that may assist if needed.

This is a unique service for people caring for someone with dementia who might have no other means of mental health support at that moment. The DCC text service is the only 24/7 live support for dementia carers in the UK.

How would people access this service?

Carers can now text 'CARE' to 85723 and receive a response within 5 minutes. There is no charge to use the service which is discreet and easily accessible because it doesn't require an app download, data registration or password and doesn't appear on a bill. Importantly for carers, that means it is a silent means of communicating and if you're worried about someone overhearing you, you can still access vital support at any time of day or night.

Ultimately, this will help to signpost more carers to our online services for much needed support, promote our brand more widely, reach new and harder to reach audiences and open doors for partnership opportunities that can also utilise this resource.

What other developments are underway?

Over the past year, we have created our online platform of training modules and with Continued Professional Development (CPD) accreditation. These courses are beneficial to everyone who cares for someone with dementia.

Every person with dementia is unique, just as the person who is caring for them. That's why we have developed online training so that everyone caring for someone with dementia can benefit from the knowledge we have learned through working with family and friends.

This, supported by our 24/7 text service for those who might feel overwhelmed, stressed, anxious or depressed whilst caring for someone with dementia, provides a unique support programme.

Dementia Carers Count works with partners to develop bespoke training courses with online and face-to-face options, coaching and 'chance to talk' sessions. We can also offer residential courses and group facilitation.

Our partners can confidently say that staff have undertaken basic dementia awareness training and have access to ongoing support. We also provide free resources for family and friends who they may be in contact with.

How can people get involved and help more carers?

We can't do this alone. The team at DCC works closely with all our supporters and partners, as well as our community contacts to develop strong, long-lasting relationships. The journey of a carer for someone with dementia is as unique as the support that we provide here at DCC and it is increasingly important that more and more people can support our work.

People can get involved in a variety of ways and we will continue to achieve more through a combination of service development, campaigning opportunities, corporate programmes and fundraising initiatives to engage with more dementia carers. If you feel you can help in any way, please do get in touch with us.

Diversity, inclusion and belonging at Dementia Carers Count

by Lissy Edwards

We are excited to tell you about our commitment to becoming an inclusive and diverse organisation, inside and out. At Dementia Carers Count we work to empower and support family carers of people with dementia and ensure their voices are heard. This means we need to work hard to connect with carers from different communities and in different circumstances. And by listening to what different carers tell us, we can make sure our services meet their needs. We are committed to building an organisation where everyone feels they belong. So when we say all carers count, we truly mean all.

Where did we start?

We began by taking a long hard look at ourselves in the mirror. A review of our entire organisation was carried out by an external Equality, Diversity and Inclusion (EDI) specialist, which involved looking at our policies and procedures and talking to us. This process helped us understand where and how we could do better to become a more inclusive, diverse and equitable organisation.

What have we done so far?

Since receiving the findings and recommendations in December 2021:

- All staff have attended EDI foundation training
- We are reviewing and updating our policies and practices, aiming for bronze accreditation on the inclusion standard Clear Assured by December 2022.
- Working much harder to find and connect with different groups of carers. And to work in partnership to meet their needs
- We have formed a cross-organisational EDI working group
- We are making sure our current recruitment of trustees is inclusive and attracts a wide range of applicants
- We want to better understand the needs of a wide range of family carers so we can tailor our services and meet people 'where they are'
- Reviewing carer data to help us identify our gaps
- We have encouraged the voluntary use of pronouns by the DCC team – for example in email signatures, biographies on the website and LinkedIn profiles

What happens next?

This is only the beginning. We have a lot more work to do, and we know we have a lot to learn. During 2023 we will create a plan outlining what we want to achieve over the next 2-3 years. This will hold us to account and drive the organisational change we want and need. We know we won't get everything right and we know we may make mistakes along the way, but we will strive to be better. Watch this space as we will update you about how we are getting on. If you want to get involved and be part of the conversation, please get in touch by emailing us at info@dementiacarers.org.uk.

Policy & campaigning

In February this year, we were delighted to welcome Helen Pyper to DCC, to lead our new policy and campaigning function. As Head of Policy and Campaigns, Helen has started to put DCC on the map for its expertise in supporting family carers of people with dementia.

In just a few months, Helen has:

- engaged with a number of MPs and peers in Parliament fighting for the rights of carers for people living with dementia. We were delighted to work with the Chair of the All-Party Parliamentary Group on Dementia (APPG) on Dementia, Debbie Abrahams MP, to produce a blog on the isolation carers can face for our 'In This Together' campaign, which also saw the launch of our campaign network
- consulted with family carers to produce a response to the House of Lords Adult Social Care Committee's Inquiry on what needs to change to create a fair, resilient and sustainable care system to outline the need for better support for family carers of people with dementia.
- launched a survey that 435 carers have responded to that will help shape the support we offer as well as prioritise the focus of future campaigns and help us reach out to greater numbers of carers in future.
- started to establish what we say about a range of issues impacting family carers of people with dementia, bringing together the expertise of DCC with the lived experience of family carers to make the case for the urgent need for improvement and outline how that change must happen.
- developed a range of tools to help campaigners, whether new or experienced, develop their skills and form part of a supportive community in which to campaign for improvements to family care.
- started to join with other organisations to strengthen our voice within wider campaigns and to make sure that family dementia carers are represented in areas where they might not always have been considered.
- engaged with DCC volunteers, family carers and professionals at local events and national exhibitions to make sure our policy and campaigning reach as wide an audience as possible.

Photo: Alexander Caminada

With these vital foundations being established, we now want to get going on campaigning for the urgent and vital change we want to see for family carers.

We know that there is a huge gap in support for the hidden 700,000 family and friends caring for people with dementia in the UK.

While Dementia Carers Count is here to fill the gap, we recognise that the services and support we offer are only part of the picture.

Through our 'In This Together' campaign, we will be building a movement for change with family dementia carers.

Our campaign is calling for all family dementia carers to receive the ongoing recognition and support they need to enable them to manage their caring responsibilities and live fulfilling lives.

We want our campaigning to have the biggest impact possible. To do this we must make sure we're raising the issues that really matter to family carers. This is why we have been reaching out to family carers to ask what they believe must change about being an unpaid carer in the UK in 2022.

Our first annual survey has been a vital way for us to hear from family carers and we are incredibly grateful to the 435 carers who took the time to tell us about their experiences and the challenges they face on a daily basis.

The results of our survey have given us a clear picture of the support family carers are telling us they need and what they want us to prioritise. Using this insight, we aim to improve the path of the typical journey that family dementia carers experience.

81% **had no choice. There was no one else to take on the caring responsibilities**

84% **have reached crisis point at least once since becoming a carer**

69% **don't get the support they need**

"I feel like I'm not 'me' anymore, just mum's carer. I know I am neglecting my own health and feel stressed a lot of the time, wondering what will happen next."

We understand the frustration of carers who find themselves being directed from service to service, having to retell their situation and never receiving the actual support they need when they need it. This is why we are constantly working to develop what we at Dementia Carers Count offer family carers.

One particular challenge carers raised in their survey responses was the difficulty in trying to balance work with their caring responsibilities.

66% **of carers were in work when they became a carer**

48% **of carers would have remained in employment longer with additional support from their employer**

Yet 28% **left work and 21 % reduced their hours**

49% **still plan to go back into work**

This is why we have joined other charities to support the **Carers Leave Bill**, which is currently being debated in Parliament, and will continue to raise this issue with policy makers to demand improvements to the support family carers in work receive.

If you would like to join us in our campaign for better ongoing support and information, tailored to family carers' individual needs, from whenever they need it, for as long as they need it, or to find out more about our campaigning please visit dementiacarers.org.uk/support-us/campaign.

> **"There's very little support out there. I feel alone. Nothing to do with caring is easy and most of this journey is a long hard battle."**

Dementia Carers Count at the forefront of resuming face-to-face carer services

New era, new needs, new format

Dementia Carers Count now has a noteworthy breadth of content which is delivered through live online sessions, the Virtual Carers Centre and Facebook live events with a growing team which brings a depth of expertise from a range of professional backgrounds.

In October 2021 we commenced a trial of face-to-face work in Brent, where Lissy Edwards, Senior Specialist Practitioner and Rachel Allen, Carer Liaison Administrator trialled the delivery of services within a community centre. Every Tuesday, family carers of someone with dementia and those they support spent the day at the community centre participating in different activities and having lunch together.

DCC worked with carers, the centre volunteers and staff to develop some sessions for this group of family members. The programme included the following themes:

- What is dementia?
- Managing symptoms: it's not all about memory
- Why dementia is different for everybody
- Memory changes
- Looking after yourself as a carer

Format

The sessions provided a very different type of delivery to the one utilised by DCC pre-pandemic when we solely ran 3-day and 1-day courses. These new sessions were weekly and were 1.5 hours in duration.

DCC was committed to setting aside time for everybody to get to know each other and to create a safe, confidential, and respectful space where people felt comfortable sharing both positive and negative experiences and emotions. Whilst each session had a specific focus, participants really benefitted from having ample opportunity to share experiences, ask questions and support one another. It was important to allow plenty of time for this within each session.

Evaluation

An evaluation form was completed by participants. Here are some examples of people's comments:

> I have learnt so much during this training on how to treat my wife

> So nice to partake in a group with other carers going through the same experiences as me

> Fantastically delivered course, thank you

> It is so important to think about your own wellbeing as well as those being cared for

> Really enjoyed and benefitted

> Try to think differently, don't take stuff personally

Danny Maher the CEO of Ashford Place has also provided some very positive feedback:

"I have to take this opportunity to thank you for your programme of training for our Brent Carers. Very rarely have I heard so many positive genuine comments from those attending with one person telling me that the programme has changed her life in terms of now having a better understanding of how her partner is affected by dementia, and how she can change her perspective and ways of supporting him. All the carers attending so far are so impressed by you and your colleague and the content of the sessions. Believe me, we have not had this quality of carer support in Brent for a very long time, and long may it continue. We are so lucky to have DCC here in Brent. We believe that if we can support the carer then they will fare so much better in caring for their loved one."

Reflections

Working in these new ways has taught us a lot about how we can shape new services:

- Carers value plenty of time to talk, share and offload. We need to be mindful to not jump in, as it can be easy to take over. Giving space for people to talk carer-to-carer is incredibly powerful and we play a role here in facilitating the creation of local support networks. We did this in the 3-day courses but had the opportunity for carers to connect during meals and during the evenings. In this new way of working, we need to build it into the sessions even more than we did previously.
- Session attendance can be far more unpredictable than through the 3-day and 1-day course arrangements, and we need to adapt, be flexible and roll with unpredictability!
- This new way of working was a hugely enjoyable and rewarding experience for the staff involved and it was great to meet people in 'real life' as opposed to online. The staff felt a deeper connection and authenticity from being in a room with people and are hopeful that these 'in-person connections' are likely to lead to further opportunities and collaborations.

The experiences and findings from this initial project have been replicated from service deliveries which have occurred across England, where we have developed and delivered short sessions for carers in Cumbria, Solihull and for paid carers within a care home environment. Further sessions are planned in all these areas, with more regional opportunities developing across the UK.

Photo: Alexander Caminada

Howard's story

I am 64 years old and live in Hove with my wife of 40 years, Deborah. We've lived in our home since we got married and have three children together. Before her illness, Deborah was a graphic designer and a keen photographer. We both love photography and music. I travelled a lot for work, so Deborah worked part time and managed our home. She was always in charge, sorting out the children and ensuring a meal was always on the table.

Photo: Alexander Caminada

We first noticed Deborah's memory issues in 2015 when she was just 58 years old, although I think she may have been masking them for a while before. She would go to the GP with her concerns, but her symptoms were dismissed as signs of menopause. She'd forget small things like where her keys were and when she was meant to meet someone, she felt confused. I decided to go with her to the GP and that's when we were taken more seriously. Not long after, she blacked out and so we were referred for a scan and, consequently referred to a dementia consultant. She was diagnosed with Posterior cortical atrophy (PCA). Her consultant was very good, signposting us to the Alzheimer's Society, where we got some help with a Personal Independence Payment (PIP) form. At this stage, I decided to go down to part time work so I could help Deborah. Her condition progressed very quickly, and when we had to start locking the door at home to keep her safe, the council became involved, and we managed to get some help in the mornings with personal care. It took two years to install a 'wet room' for Deborah, which sadly now she cannot use, as it is upstairs and she's no longer able to get up the stairs. In the earlier days, my daughter and I trained Deborah to use the toilet at regular intervals, but now she uses pads.

Our children have been a great support. Our son currently lives with us and gives Deborah her evening meal, our daughter works but helps out when she can, and our other son doesn't live as close by but visits every weekend. More recently Deborah has been having seizures which can occur at any time of the day. Now we have two carers come in four times a day to help us with meals, personal care and medication. I always offer them tea and appreciate the extra pair of hands. We also have as much as possible at home for emergencies, so that if something happens paramedics can act onsite, rather than take Deborah to the hospital. Our GP is very helpful, helping us put in place a 'ReSPECT'** form, which is a good thing to have if you want to avoid being taken to the hospital.

I knew I wanted to support Deborah at home for the rest of her days. Every day brings new challenges, some high, some low, and I sometimes feel I am on a rollercoaster going up and down so fast and never ever being able to get off. I put my own health issues second, I have lymphoma, so my illness sometimes does hinder my caring role. I can feel angry, tired, low and burnt out all at once.

My daughter made me aware of Dementia Carers Count (DCC) and we both attended a DCC 3-day course in 2018. I had to get some respite care in place so I could attend. Deborah was still able to walk, eat and talk back then and I was able to get nine hours of respite care from the council, combined with my son taking some time off work to help. I felt she was safe so I could attend without worrying. Initially, I was nervous about it, but we were warmly welcomed by the course leaders, and it was wonderful meeting the other carers. The sessions were very interesting and I recall the lady coming in to speak specifically about benefits and finding it very useful. I particularly enjoyed the breathing exercises and mindfulness skills.

As a group, we struck up a friendship and even started a private Facebook group, keeping in touch with each other after the course. It was great to share experiences, we really bonded. In the evenings we ate together and had a laugh, talking about other things. The main thing I came away with was knowing that I needed to make time for myself and that that was okay. To share the load if I could. I realised that I had stopped doing things for myself such as my photography and even reading. Now I take the time to go to the woods on my own, enjoy nature and continue to pursue my love of music.

Small things can build up until you feel you can no longer cope with even the simplest of tasks. My advice to carers who find themselves in the same position as me would be to seek support through DCC's services. What I learned enlightened me, it opened my eyes and mind and helped me keep myself well. After all, what use would I be to Deborah if I end up unwell too?

Deborah is now at the end of her life and we don't know how long she has but she is at home surrounded by people who love her. I'm grateful for that and to DCC for helping me on my journey.

Sadly Deborah died earlier this year. Our thoughts are with Howard and his family. He continues to serve as a DCC Ambassador, ensuring as many people like him as possible know about our services.

**ReSPECT is a national patient held document, completed following an Advance Care Planning conversation between a patient and a healthcare professional. Central to the ReSPECT process is a two-sided form, which allows clinicians to record a summary of discussions with patients about how they want to be treated in an emergency.

Who we are: Staff team, Board and CAP

Trustees

Catherine A’Bear
Chair

David Goodridge
Vice Chair

Tony Burch

William Burnand

Richard Drummond

Julie Flower

Gaynor Hillier

Darren Humphreys

Haider Husain

Darren Garner
August 2017 to June 2022
In June 2022 we gave thanks to Darren Garner, who has served as a trustee for five years.

Senior Leadership Team

Claire Goodchild
Chief Executive Officer (2015 - 2021)

Claire Goodchild died in December 2021 after several months of illness. Claire was instrumental in building Dementia Carers Count (DCC) to continue the Royal Surgical Aid Society legacy, with a renewed focus on supporting unpaid family carers of people with dementia. From 2015, Claire worked to develop DCC and its services, starting as a team of one and building the organisation from scratch; DCC launched officially in 2018. Claire had a strong background in social work, specialising in working with people living with dementia. She began as a passionate, committed and talented student, embracing the person-centred approach to care and the social model of dementia that were emerging at the time. Claire even had her placement project published in the International Journal of Geriatric Psychiatry in 1996 – an accolade few students could match. Claire led numerous national and regional programmes relating to health and care services for older people. As a member of the Department of Health team that led the implementation of the National Dementia Strategy, she was the catalyst to numerous innovations in dementia; including creating a social movement of people with dementia that led to the creation of DEEP and pioneered Dementia Friendly Communities. Claire’s huge contribution to the dementia field, her personal style and her frequent laughter will be greatly missed by all who knew her, and by the wider dementia community. ‘It has been a privilege to know Claire and to work with her in developing the services of DCC. She will be greatly missed, but her passion for helping and supporting others will be a lasting legacy.’ – Ming Ho, Chair of DCC’s Carers Advisory Panel.

Melanie Blanksby
Acting CEO from June 2021

David Warren
Interim Director of Finance
February 2021 – April 2022

Steve Dubbins
Director of Services

Lara Cooper
Director of Communications & Marketing

Tom Espley
Director of Finance & Resources

Mankit Yau
Director of Development

Carers Advisory Panel (CAP)

The members of our Carers Advisory Panel (CAP) 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

Mah Rana
(from Jan 2022)

Heather Dowler
(from Jan 2022)

Photo: Alexander Caminada

In conversation with trustee Tony Burch

Tony Burch

How would you reflect upon your time as a trustee at DCC?

I've been a trustee for seven and a half years, eight years by Christmas when I will sadly be leaving DDC. I remember joining DCC a year after I retired from working as a GP for 30 years and it's been quite an interesting ride since then. The charity has changed beyond all recognition. We've had our ups and our downs, but I feel that we're in a very healthy and good place now and the next two years are expected to be really interesting. When I am no longer a trustee, I will still keep in touch with what's going on. I think the charity's in a really good place.

There was a bit of a shock to the system for everybody when Covid hit, wasn't there?

We've had our ups and downs, including Covid which was a terrible shock. The office had to close, the courses had to stop and it felt like we were suddenly not able to do anything, so there was a scramble to get an online offer, which I think is now really quality stuff.

We've had to rethink our offer in the last couple of years and that is still a work in progress. But what I find exciting is that all these other ideas are bubbling up, some of which have been implemented, while some are still in the design stage. At the time I remember thinking it was a bit catastrophic but we've responded. We dusted ourselves down and got on with the job.

So, do you think being adaptable and proactive was key to the evolution of DCC?

Indeed, we have barely got ourselves established in lots of ways - in what we see as our main role - Dementia Carers Count. I love our name, by the way, it says what we do on the tin. And so we've had to think about what we do in different ways from some of the more established charities that already have a foothold. We haven't really had much of a foothold and so that's been additional pressure on us.

What was it that first attracted you to the role?

I was a GP, and my two main clinical interests were in older people and mental health and they met in dementia. Before I was ever approached by DCC I had been involved in advising on the recommissioning of our local memory service offer in Brent in North West London and I've done quite a lot of teaching on dementia. It was what used to be called the Cinderella service, and a lot of GPs didn't really know how to manage memory loss, cognitive decline and dementia. As an educator, I was well-placed to help inform my colleagues.

Someone who knew me through Age UK, where I was also a trustee, put me onto DCC. It was a good fit and I've been very happy to transition away from paid work. It's been a very good thing for me to be doing and I've had seven and a half happy years doing it.

Will you be sad to leave your role as a trustee?

I'll be really sorry to leave the charity, yes absolutely. The next two years are going to be particularly exciting for DCC. However, I'm a firm believer in there being term limits for trustees, and I don't want to outstay my welcome. I think we've got some really strong trustees, especially new ones. With this admirable Board in place, it's time for me to step away and for someone else to replace me. I just have to manage my sadness at leaving. I hope to keep a close eye on and interest in what's going on because I do think the charity's got a really strong future and I am excited to see what happens.

How have you seen the organisation change and grow during your time as a trustee?

When I joined we were still running three or four care homes under the name Age Care. The concept of Dementia Carers Count was merely a concept. Not a single employee from Age Care stayed - only the Board remained. So it was 'all change'. I wasn't involved with the sale of the care homes, but what we did the following year was to appoint our first Chief Executive, Claire, who then had to build a new team around her. It is still growing, still developing, so in that sense, we were a startup. I knew we had some money in the bank and I knew that we had the Board, but otherwise we started with a clean slate. So, what changed? Everything changed, and I was part of that. Five years of seeing the charity grow in terms of staff numbers, and range of activity, getting more confidence, developing different strings to our bow and, more recently, thinking about the next steps again, so it's been (and continues to be) a constant evolution.

You were instrumental in developing Dementia Carers Count's partnerships with Ashford Place and Brent Carers. Tell us about these partnerships and your role in the success of this work.

A huge amount of work and activity has been going on in Brent that I have been part of. There was a new charity called Community Action Dementia Brent, which persuaded the Council to sign up to become a dementia friendly borough. There were a number of 'dementia cafés' which opened up and survived the lockdowns. I was very happy to be involved, partly with my clinical hat on and then later with my charity Trustee hat.

There is a strong, community based charity in Brent called Ashford Place, whose chief executive, Danny Maja, is the chair of Community Action Dementia Brent. They run various successful initiatives such as dementia cafes, and other outreach activities around people living with dementia and their carers. When we were looking to pilot a regional base for operations, it made sense for me to speak to Danny and ask if he was interested in hosting one of our staff to run courses for carers. DCC's Lissy Edwards went down a storm and it was just brilliantly successful and popular. It stemmed from my contacts there, and things were ready in Brent for that to happen. I was delighted to be able to make that happen. Although my work as a Trustee has been varied, I was able to draw on my experiences from my previous life which allowed me to make what I hope has been a positive contribution and to join in on the excitement and the energy around it. It's been brilliant.

So what's the next chapter for Tony Burch?

I finally gave up paid work just over a year before the pandemic - I was in another educational post after my clinical ones. I had a year of waking up every morning and thinking, "oh, I'm on holiday". This 'holiday' came to an abrupt end during the last two and a half years and I have led a very different existence. I'm about to catch up on my summer holidays by taking most of the next month off and thinking about what I do next. I am also finishing up with another charity that I've been volunteering for, but I am also involved in a mutual aid, community gardening scheme. What I do next may be something different, it may be something quite creative, or I may learn a language - which is instantly very good for making new connections in the brain, and I'm keen to keep my cognitive skills up to scratch. In short, I haven't decided yet, but I've got the luxury of having some time to make up my mind.

If I were to learn a new language I think it's got to be Italian. I just love Italy. It's such an old country...its buildings, the history, the wonderful music and fabulous food.

Final words

I had a great time. It's been quite challenging, but I've really enjoyed the ride and I think I've had something to offer. I've also learned a great deal. I think that's the most important thing. You learn as you go and transitioning from an old charity to a fledgling charity was an incredible journey.

It took me a while as a GP to realise how important family carers are. By the time I was gearing up for a role at DCC, I was well and truly behind in supporting carers as a priority. Carers get created, they step into a role when the need is there, they haven't thought about it before, they just know that this is something they have to do (some want to do it), and so they're pretty unprepared.

> **"You get plunged into it, and you become an expert obviously in the medical condition around dementia, but also you've got to manage yourself as a carer and more often or not carers are ill equipped for that. That's where DCC steps in".**

Tony is a retired GP in NW London. He is also a trustee of his local AgeUK, and involved in Community Action on Dementia in Brent.

Kelly's story

I've been going to my grandma's for supper every Wednesday since I was two years old. My dad used to bring me and my siblings, but now I'm the only one who goes. My grandma and I have always been close, but when I was 18 my mum died, and since then, she's become more of a motherly figure.

My grandma was always on the go. Even when she was 88 or 89, she was out every day — shopping, going to church and meeting friends. At first, I noticed that she didn't want to go out and was becoming a bit forgetful but she could still take care of herself. Then she had two bad falls and, by that time, I'd told the doctors repeatedly that she was struggling with her memory. Nothing happened until she was hospitalised. The nurses noted on her discharge letter that she had been very confused. That got the ball rolling and a nurse visited her for a memory assessment.

I was devastated when Grandma was diagnosed with mixed dementia but she's never been emotional about it and just wants to get on with things. Now, I visit her twice a day, every day. I also run my own business and am a foster carer, so things are busy. I would be grateful for more support from anyone, as most people don't realise how much help Grandma needs. Between her neighbour and I, we sort out all her meals. I help her wash, make sure she's taking her medication, pay her bills and clean her house.

Every day is like Groundhog Day, I have to be at Grandma's at certain times. After lunch, I know I have four hours until I have to go back over to her, so it's hard to take any time for myself. One of my good friends is getting married this year and I can't go to her hen party because it's in Milan and even the wedding will be difficult to attend. My grandma's stepson is travelling for over five hours to spend the night with her while I'm away. It's almost easier to just stay here and miss out on everything.

I've been going to Grandma's twice a day for 15 months now. Everything I do revolves around her care and I don't get any support from social services. Grandma is a very proud person, and I don't think she'd accept a formal carer. If it wasn't for her neighbour, I'd be doing it all alone. My life is very restricted and I feel isolated but I've got to get on with it.

I know it would probably be helpful to attend a carers' group, but it just feels like another thing to add to my list. I still need to work during the day and attend foster meetings, so I don't know how I'd fit it in. I found out about Dementia Carers Count (DCC) in a Facebook group for carers. Someone had shared a link to the Live Online Learning sessions and because they were on at different times of the day, I could find ones that worked with my schedule.

When I first attended I was a bit anxious. I thought it might be a teacher/student environment, and I'd be put on the spot and have to answer questions but it wasn't like that at all. You don't have to turn your camera on or even speak if you don't want to. The course leaders put me at ease immediately; you can tell they are good at their jobs and know what they're talking about. It feels like a group of like-minded people coming together to learn about dementia, ask questions and share their experiences. Having the opportunity to spend time with practitioners with medical knowledge and experience of dementia really helped. Once I attended the first session I wanted to do more.

Dementia is misunderstood, and I find it difficult to talk to people about my grandma because they don't get it. During DCC's sessions, everyone understands. You don't have to pretend things are ok, and you don't feel ashamed if you get emotional because everyone is dealing with the same thing. You can share things that are really raw and you might not be able to do that elsewhere. You feel encased in a solid ball of support.

When you're caring for a family member with dementia, your emotions are heightened because you have that family bond. DCC's sessions really helped me with that. Now I can't remember the last time I felt frustrated but it used to happen every day.

I've gained a knowledge base that I can build on. I used to worry about the future but now I've learned to take one day at a time. The future is unknown, and everyone's journey with dementia is different.

Each session gives you a circle of friends. Even if you never see some of the other carers again, in that space and time everyone is in it together and I looked forward to that peer support too.

> **"Being a carer is a hidden role. Even though my family knows about it, they don't know what it's like. A lot of carers might feel like no one cares what they are doing, but DCC does care. When you sign up for a DCC course, you'll get more out of it than you can imagine".**

Photo: Alexander Caminada

Fundraising and community work

This period has been one of growth for Dementia Carers Count, not least within our income generation team with the appointment of four new members of staff.

A great deal of our work this year has been about consolidating what we do well, and what is working, whilst using the resources that we have efficiently and productively. These past few months have been creative and full of energy. We have continued developing our grants programme and have been fortunate to receive a number of gifts from trusts and foundations including from the Linbury Trust and the McLay Dementia Trust who have both given to us for the second year in a row. Projects that trusts have supported include our Virtual Carers Centre, regional face-to-face delivery of services, and our new text service which was partly funded by the Ernest Hecht Trust – this particular grant was awarded with the help of one of our wonderful Ambassadors, Barb Jungr who lives with and cares for her mother who lives with dementia. Barb knows all too well the importance of our work and the vital need for support for carers.

Future grant funding will go towards our new initiatives including service delivery in Scotland, translation work (starting with Welsh) and also our new telephone service.

Photo: Steve Ullathorne

Community work continues with Yael's visits to various groups including u3a meetings; the Association of Jewish Refugees; Rotary Clubs; and presentations to Women's Institute groups. This form of engagement work means we meet more people, increase awareness and raise the profile of our charity. It can sometimes, if we're lucky, generate crucial income so our work can continue and develop.

Yael receiving a cheque from Winslow Rotary Club at The Winslow Show August 2022

We were delighted to have welcomed a number of fundraisers including those who took part in our second Every Small Step event, and even a brave marathon runner, Chris Gray who raised £1,092 for us. He chose us because his mother benefited and continues to benefit from our free courses.

> **...My mum ... took part in one of your online courses recently. My dad is in the early stages of a dementia diagnosis - the signs are pretty obvious at this stage and the nurses are confident he has vascular dementia - but we're of course a victim of the prolonged waiting times waiting for a brain scan. My mum is now his carer. My Grandma (her mum) had dementia, so we've been down this path before and know the signs...**

With the new team, we are planning even more activity for next year with plans for our fifth anniversary celebrations already taking shape. Creating a new programme of events for 2023 means we are engaging in new ways with:

Schools, Universities and Colleges

In 2022 we launched our new education outreach programme making connections and forging new relationships with educational organisations. This includes supporting them with their fundraising and raising awareness of our work, while offering support and advice.

Care Homes

As our commercial business grows, we are also reaching out to care providers and we know that there are so many ways that we can partner with organisations from delivering face-to-face courses in new areas of the country, serving new groups of carers and supporters, as well as engaging the community in fundraising whether through coffee mornings, sales, or sponsored walks. This will be developing in 2023, enabling us to increase reach, influence and income generation opportunities.

Carers Groups and individuals

2022 has seen new opportunities to speak with larger numbers of community groups across the country from Cornwall to Cumbria, and with our new charity registration in Scotland, we are looking forward to working in the region with our services team as they begin to deliver face-to-face work and we engage the community to raise awareness and fundraise.

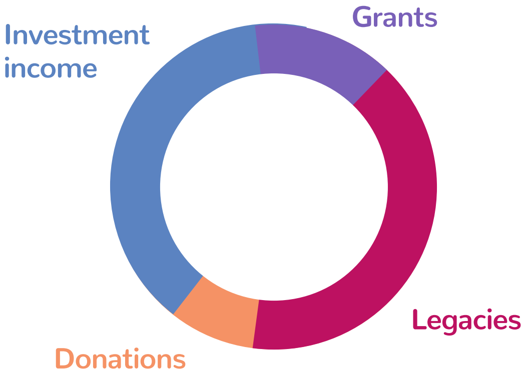
Partnership organisations and new collaborations

We have worked hard to build new and lasting partnerships and collaborations, enabling us to plan joint fundraising activities with organisations which share our vision and ethos. This will enable us to further expand our fundraising goals and achievements in 2022. We have also partnered with a number of organisations that are supporting us in fulfilling our fundraising vision including Go Skydive, Charity Challenge, Muchloved and Farewill. There are so many ways supporters can support Dementia Carers Count – whether it’s a coffee morning, gaming, climbing the 3Peaks or a skydive – we are looking forward to meeting many more people in the next 12 months and supporting them with their fundraising.

Historical financial information

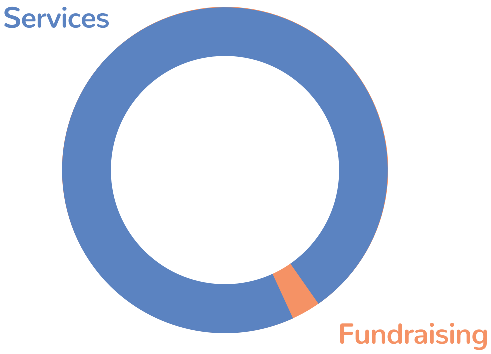
Total Income

£618k



Total expenditure

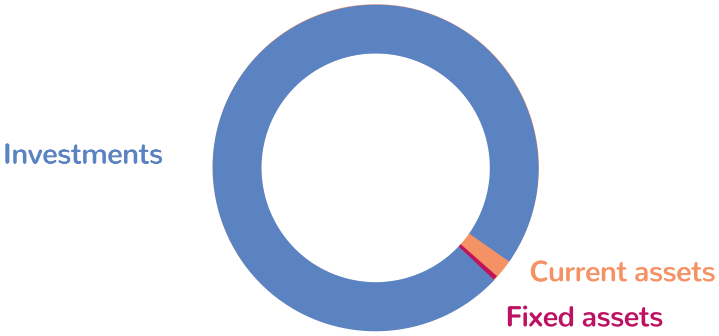
£1,251k



Net Assets

£9,782k

DCC's assets on 31 December were £9,782k - most of which is made up of investments



Net Operating Expenditure

£633k

Net operating expenditure represents costs for the delivery of services and building the organisational infrastructure to support DCC's new strategic direction.

While expenditure exceeded income by £633k, DCC's investments increased in value by £452k, so the overall drop in funds was £203k.

Funds

Designated funds	£9,098,000
General fund	£684,124

Total Funds

£9,782k

DCC's funds have been designated, to help ensure the long term strategic direction and success of the organisation.

Significant investment in people and operations is needed for the delivery of DCC's strategic plan, which can be covered from DCC's reserves.

The general fund is £684k, representing funds needed for day-to-day operations.

Closing words from Acting CEO, Melanie Blanksby

Melanie Blanksby

2022 saw a significant change for DCC as our team began to implement our new approaches to reaching family carers and our organisation grew to build the skills and resources to underpin these. We continued to strive to reach more carers with the services that they need and to evaluate the ways we can become financially sustainable.

We welcomed new team members around the UK and our board recruited new trustees as well as thanking trustees who have stepped down this year after providing many years of counsel; some since the Royal Surgical Aid Society (our parent charity) chose family dementia carers to be our beneficiaries in 2015.

This year we saw coverage of the evaluation carried out by the Association of Dementia Studies at the University of Worcester research into our original three-day courses, in both the Journal of Dementia Care and in Dementia: the international journal of social research and practice.

We have begun to develop our commercial portfolio for partnerships, paid carers, care homes, employee support and a range of training packages. We have innovative partnership work underway with the Aston Villa Foundation, The Good Company People, Forward Carers Birmingham and the British Embassy in Thailand.

Our first dementia carer survey results in Autumn 2022 gave valuable insights into how family carers of people are coping, and the support needed. One key insight is that over 80% of family and friends caring for people with dementia are reaching crisis points and not getting the support they need. Furthermore, one in five family dementia carers are reaching crisis point on a regular basis and family carers shared that they feel "alone", "trapped" in a life they have not chosen and "broken". Respondents also confirmed that the majority of carers have not chosen their caring roles, the caring experience is intense, and most carers lack support.

From 2022 our three strands of support are defined as: emotional, practical and dementia understanding and financial and legal. Carers will increasingly be able to choose how to access support from face-to-face activities with our team in locations around the UK, via our free 0800 652 1102 support line number, and via live and on-demand digital content on our website and through our social channels.

As the DCC team prepares to increase our provision in 2023 for those looking after a partner or family member with dementia, and the families, friends and communities alongside them, we confirm our commitment to provide consistent support in the places and formats that carers prefer and that we continue to listen to carers and strive to meet unmet needs in line with our heritage since 1862 when our founder first developed the Royal Surgical Aid Society.

I will continue in place as Acting CEO while the needs from the permanent CEO role are defined, with recruitment to this post in early 2023. I look forward, together with our DCC team, to working with our growing community of carers, supporters, donors, volunteers, and commercial partners as we scale up our delivery in 2023.

Melanie Blanksby

Acting CEO

ANNUAL REVIEW

2022

Acknowledgements

Baron Davenport's Charity
Bernard Piggott Charitable Trust
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Gledswood Trust
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Kelton Trust
Lennox Hannay Charitable Trust
Linbury Trust
Masonic Charitable Foundation
McLay Dementia Trust
Oakdale Trust
Roger & Jean Jefcoate Trust
The Batchworth Trust
The Chapman Charitable Trust
The Morrisons Foundation
Thomas Roberts Trust
UKH Foundation
William Arthur Rudd Memorial Trust
Winslow Rotary club

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CARERS COUNT
Supporting Family Carers

dementiacarers.org.uk

Dementia Carers Count is the working name for The Royal Surgical Aid Society
Charity registered in England & Wales (216613) and Scotland (SC051929)
Company limited by guarantee, registered in England and Wales (515174)

Charity registered in England No. 216613