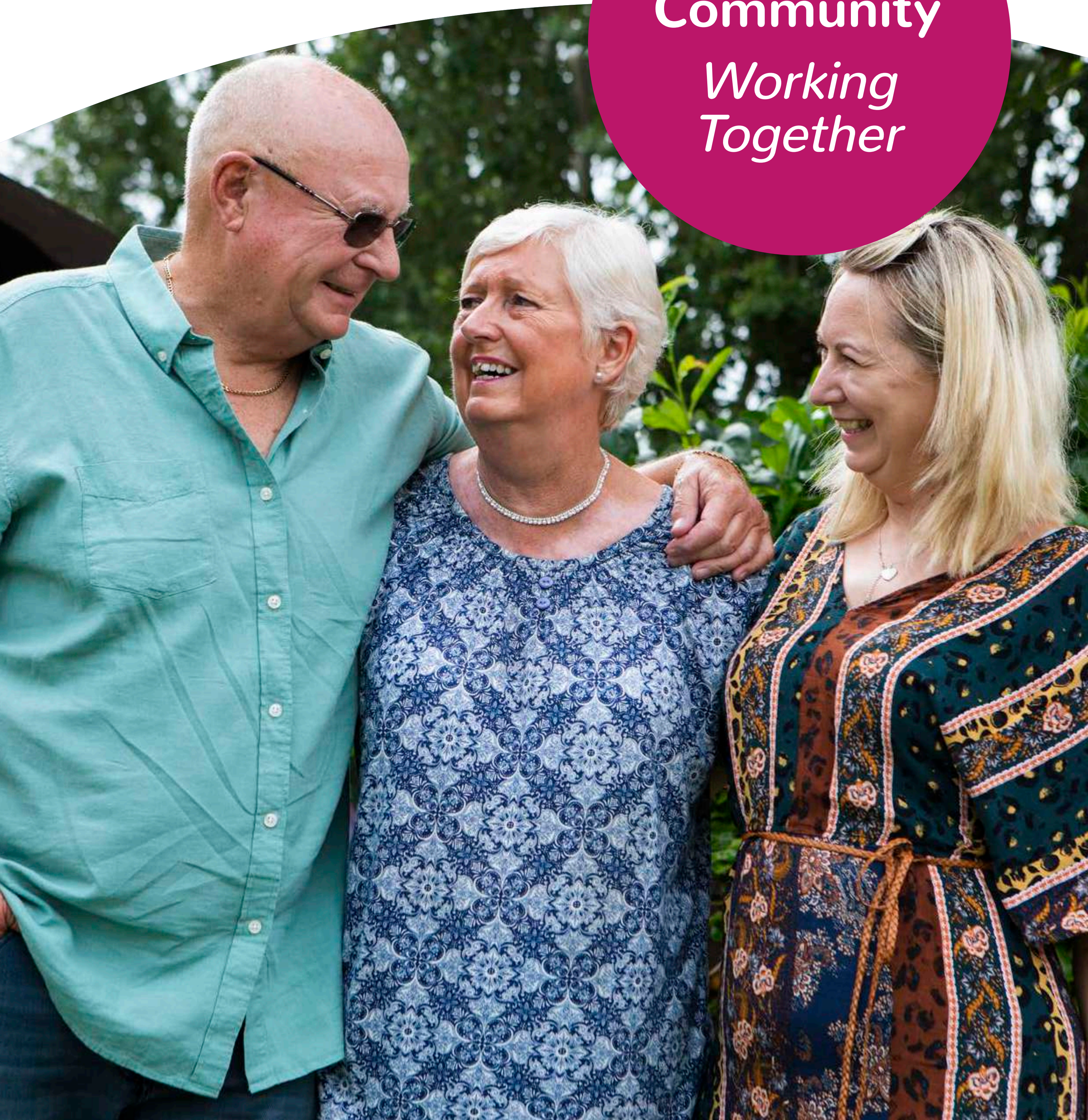
2020
ANNUAL REVIEW

DEMENTIA
CARERS COUNT
Supporting Family Carers



Building Community
Working Together

Welcome from **Amanda Houlihan**

I am delighted to be presenting our second Annual Review and exceptionally proud of our charity's fantastic achievements, during what has been an incredibly challenging time for our beneficiaries and the charity sector in general.

The theme for our year ahead is building communities and working together.

Little did we know last year what 2020 would bring us in terms of the way our daily lives have had to change. Community spirit feels more important than ever.

Since last year's review, the DCC team has been continuing to work toward our long-term goal of enabling every family carer to access our services, no matter where they live.

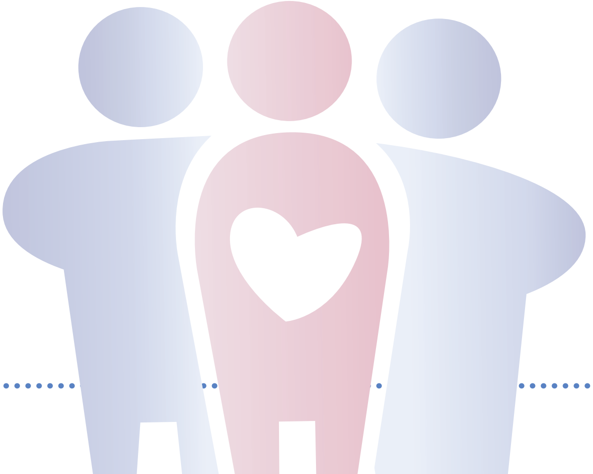
We are also working towards the establishment of our national centre of excellence in the form of the Dementia Carers Centre. Our team may be small, but our resolve and ambitions are anything but.

Observing the staff team navigate the challenges of delivering courses during the pandemic has been an inspiration. The interruption of course delivery evoked an impressively rapid response and the development of the Virtual Carers Centre quickly engaged the wider team, course alumni, and volunteers. I am delighted that the Virtual Carers Centre has meant that we can continue to reach so many carers. I believe it will be a positive and lasting legacy from these testing times.

I would like to take this opportunity to offer thanks to my fellow trustees for their focus and concerted efforts. We continue to work as a team to ensure that the charity operates to the highest standard. This collective commitment means that beneficiaries and supporters can expect the professional and high-quality services they need to make a difference.

This year's annual review will give some insight into just some of the things we have accomplished together this year. Working together is at the heart of what we do, after all. Through our teamwork within the organisation, bolstered by the external support and invaluable input from our dedicated volunteers and Ambassadors, we can be confident that Dementia Carers Count will continue to grow to become the far-reaching organisation we all envisage for the future.

Amanda Houlihan,
Chair of the Board of Trustees



Our mission

To provide a welcoming environment for family carers of people with dementia and inspire them to learn and connect with each other.

To make sure they receive the training and develop the skills that will empower them to continue caring for others and themselves.

To continue to invest in research that will help us to better understand family carers' experiences, needs, and outcomes.

Our vision

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

DEMENTIA CARERS COUNT
Supporting Family Carers

David's story

2020 was marked by the COVID-19 lockdown. This is David's account of his experience.

It's been 108 days since I saw my wife. She went into respite care a week before lockdown began. I visit every day to bring fruit, puddings, and cakes, but I never actually see her.

I've known Jane since she was 14. When she turned 18, we started officially going out and got married when she was 20. I've worked on farms all my life and I drove a truck when our four girls were little, so I could spend a bit more time with them. My wife has always worked in a school and she was a highly regarded member of staff. Unbeknownst to me, they had started to carry her but didn't like to say anything. They eventually suggested she take early retirement.

That was all before the diagnosis.

I didn't notice the changes at first. When you're always together, it creeps up on you. Every day, Jane would walk the dog and every day we lost the front door key. I lost count of how many fobs and keys we had to replace, but I still didn't register there was anything wrong.

It all came to a head on a family holiday to France in 2016. Our twins took me to one side. "Dad, there's something really wrong with Mummy", they said. "You've got to get her checked out".

Another year and a change of GP later, we received the official diagnosis. "If you've been saving for a rainy day, this is it", the consultant said. "Get medical and financial power of attorney and do all the things you've been wanting to do soon before it's too late".

I've worked all my life and wanted to take care of my wife. By this time, I'd already left work to care for her full-time. I couldn't leave her on her own. When she tried to cook, she'd burn everything. If you knew Jane, you'd know that wasn't her. I was worried she'd hurt herself. Jane used to do everything around the house. She cooked like it was no effort, and everything was delicious. I used to say: "I really appreciate this", but I never realised how hard it all was. The washing, the cleaning, knowing what to eat, and what makes a balanced diet. I'm ashamed to say, I didn't even know how to use a washing machine.

I thought I could fix it all on my own, but I couldn't. We hadn't seen anyone in the medical profession since the diagnosis and I had to advocate and fight for all the benefits we could get. I went to several charities to try to get help before I found Dementia Carers Count.

The three-day residential course they provided re-adjusted my thinking and it has helped me to cope. It's been such a journey and made me realise that you need to ask for help. If you think you can go it alone, as I did, you could soon find yourself up the creek without a paddle.

I thought the course was going to be a real trial, but it was quite the opposite. The mindfulness and coping strategies I learned have made all the difference to me. I started practicing back at home whilst putting out the washing. Focus on the task at hand, don't dwell on your problems. I'm still living off the encouragement I got from the course leaders. Being told that I am doing a good job by people who are knowledgeable and understand dementia has completely shifted my mindset. They were genuinely interested in everyone on the course and for the first time in ages, I felt like someone was caring for me.

The experience has helped me get a better perspective on my situation and has stopped me from wallowing in self-pity and thinking "I'll never cope".

> *"The course revived us. It was fantastic. I'm a complete advocate and would recommend it to anyone and everyone in my position."*

You can help more people like David feel supported and confident in their caring role. By giving a regular gift you'll ensure that family carers can access our services at a time when they feel most alone.

When I first arrived at the hotel for the course, I met a lady who looked like she had the weight of the world on her shoulders. Looking back, I think I must have looked the same. Over the three days we were there, I watched her transform. She hadn't had a break for over 10 years and knew as little about taking care of herself as I did. The course revived us. It was fantastic. I'm a complete advocate and would recommend it to anyone and everyone in my position. You're doing yourself a disservice by not attending.

Jane was at home with me until three months ago. I was feeding her, changing her, and getting her to drink. She'd forgotten how to swallow. At the care home where she is now, they leave plastic tumblers and cartons with straws in front of her and she's drinking on her own again.

I've bought a portal, which the carers have set up there, so I can speak to her. It can often be a one-way conversation and some days she doesn't say anything at all. I have strategies in place to deal with my feelings now, and I understand things from Jane's point of view much better now too. I definitely have a much deeper understanding of what she's going through.

Rather than thinking too far ahead, nowadays I'm taking things one step at a time. Dementia Carers Count has helped me re-evaluate how I look at things. If you're feeling nervous or unsure about reaching out to them, don't be. The benefits far outweigh whatever you think the cost might be.

> *Dementia Carers Count has helped me re-evaluate how I look at things. If you're feeling nervous or unsure about reaching out to them, don't be. The benefits far outweigh whatever you think the cost might be.*

This year we're celebrating 158 years of reaching unmet needs in our communities

Since 2015 we've been very busy...

RSAS
Royal Surgical Aid Society

2015

DEVELOPING SERVICES FOR FAMILY CARERS

RSAS formally shifts focus from providing care homes to developing services for family carers of people with dementia

2016

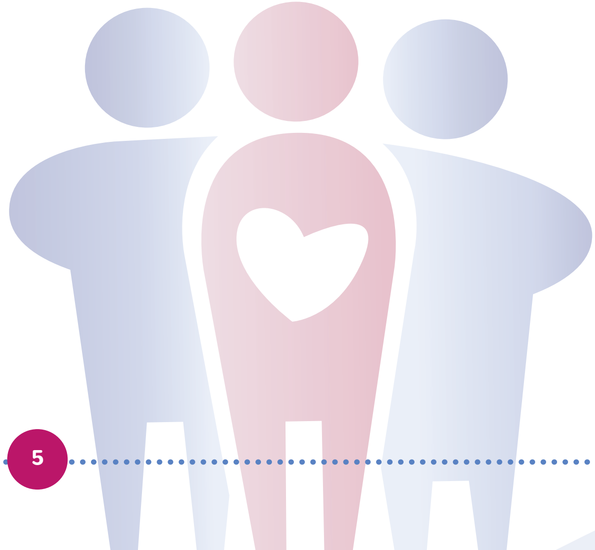
NEW VISION

The national Dementia Carers Centre vision is born

2017

EXPERT-LED COURSES

We develop and deliver our first three-day, expert-led courses



2018

COURSE EVALUATION

An evaluation of three-day courses is commissioned

2018

APPOINTMENT OF PROFESSOR

The first Professor of Family Care in Dementia is appointed

2018

REBRAND

We rebrand as Dementia Carers Count

2019

COURSES ENDORSED

The evaluation of our three-day courses is published to great acclaim

2019

CENTRE LOCATION CHOSEN

The West Midlands is chosen as location for the Dementia Carers Centre

2020

BUILDING COMMISSIONED

The building of our Dementia Carers Centre is commissioned

2020

VIRTUAL CARERS CENTRE

COVID-19 crisis affects the world. DCC launches community engagement programme and Virtual Carers Centre to support carers in uncertain and challenging times

Dementia carers: the UK stats and facts

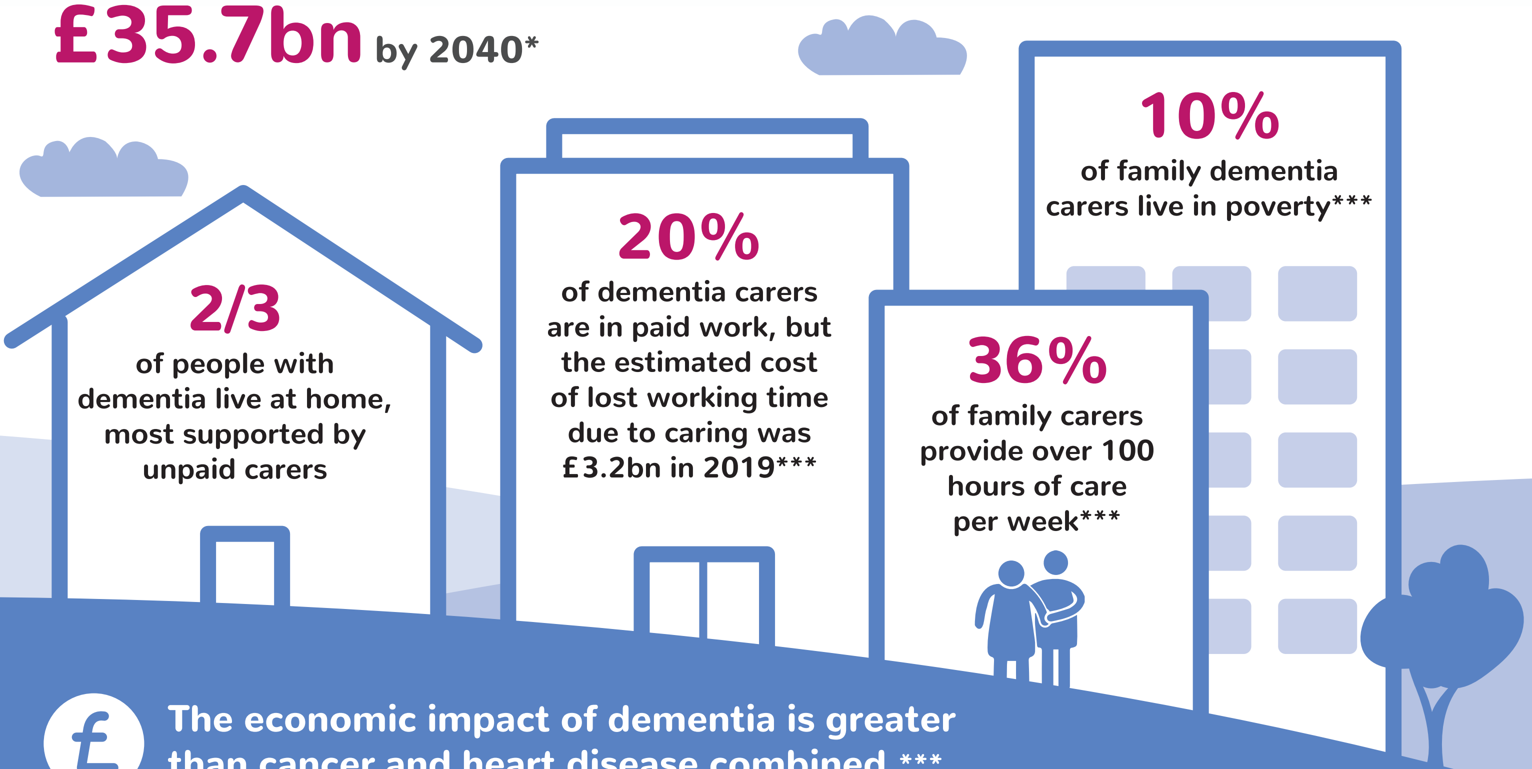
There are **700,000** family carers of people with dementia.

This figure is set to rise in line with the number of people who will develop dementia, currently **850,000** and expected to increase to **1.6m** in 2040.*

'Unpaid carers', or families and friends providing care to their loved ones, are providing care to a value of **£13.9bn** a year.*

This will increase to **£35.7bn** by 2040*

Unpaid care will contribute 38% of **£94.1bn** by 2040**



2/3 of people with dementia live at home, most supported by unpaid carers

20% of dementia carers are in paid work, but the estimated cost of lost working time due to caring was £3.2bn in 2019***

10% of family dementia carers live in poverty***

36% of family carers provide over 100 hours of care per week***

The economic impact of dementia is greater than cancer and heart disease combined.***

Sources: carers.org.uk, 2018

*Alzheimer's Society Dementia UK 2014 report updated in 2019 to predict trajectories up to 2040 using the 2014 data. Therefore, figures are best estimates of the current position of play.

** Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040

*** Cebr report for Alzheimer's Society, 2019 - the economic cost of dementia to English businesses

About Dementia Carers Count

There is a huge gap in support for family and friends caring for people with dementia in the UK, and while caring can be an enormously rewarding role, it can also be an extremely stressful one for those who do it day after day so tirelessly.

The wellbeing of carers is at the centre of our mission and we are striving to be the UK's 'go-to' place to get support. We hope our Dementia Carers Centre will offer a national 'home' for more and more family dementia carers here in the UK.

- DCC supports family, friends, and partners in the UK who are looking after someone with dementia
- As a national charity, we support all carers across the country
- By 2024 we aim to be helping 5000 carers every year
- We offer the life-changing education and skills development services our carers deserve
- We carry out extensive research to identify our carers' needs and develop our services to meet these needs

Strategic objectives for 2019-2022

A strategy for better care

- A long-term and sustainable financial strategy
- Dementia Carers Centre: the place where dementia carers can drop their shoulders
- Effective and far-reaching evidence-based services
- DCC is the 'go-to' place for dementia carers

To reach our strategic objectives we will focus on:

- Transforming the lives of carers and the carer experience with innovative and inspirational services
- Develop a better understanding of the experiences and needs of carers through focused research

Gathering the insights to support our carers

This year our approach to research has embraced remote involvement with carers. Online resources and telephone contact have replaced face-to-face group events or meetings with individuals. Our carers have provided insights to help us develop the most effective ways of supporting them.

These include:

- Personal care and bathing
- Experiences of being unable to visit care homes during lockdown
- Psychological therapies
- Employment
- Virtual reality
- Accessible film-making

Accessing vital funding

Our Professor of Family Care has led research projects and contributed to several research funding applications. Two of these applications focused on the impact of COVID-19.

Three successfully funded studies...

2020-2022

Co-applicant (Carer Involvement Work Package Lead) - NIHR Research for Patient Benefit - Evaluation of the feasibility of an RCT of Empowered Conversations: a training to enhance relationships and communication between family carers and people living with dementia, NIHR.

Total funding £291K

15% of this funding is directed at carers

2020-2022

Co-applicant (Carer Involvement Work Package Lead) - NIHR Research for Patient Benefit (Social Care) - Exploring how the naturalistic skills of care workers impact on the well-being of residents in care-homes: a micro-interactional study, NIHR.

Total funding £113K

15% of this funding is directed at carers

2019-2020

Principal Investigator - CHARM – Care Home Action Researcher in Residence Model implementation and evaluation, Alzheimer's Society.

Total funding £92K

10% of this funding is directed at carers

Our three studies covered family carer training and people's interactions in care homes.

A PhD studentship focused on dementia Meeting Centres.

Unsurprisingly, the pandemic has impacted the research world, with decisions on funding applications delayed or kept under review.

The launch of any new funding rounds, which usually take place throughout the year, have mostly been suspended. Many existing research studies have been asked to adapt to include a focus on COVID-19, where possible, and there has been a surge of new funding opportunities around prevention, treatment, and recovery from the pandemic.

Our current CHARM study, Care Home Action Researcher-in-Residence Model, has been paused mid-way because of the pandemic, but not before being praised by the funders for adapting so well to lockdown.

The Alzheimer's Society and the Dunhill Medical Trust both asked for help in responding to the challenges faced in their funded studies, and our CHARM study team stepped up.

They shared the different ways they had adapted to supporting the four care homes in the project remotely, including switching to working on end-of-study activities, such as final report drafting. They even sent cookies to care home partners by way of support. The Dunhill Medical Trust turned these CHARM ideas and others into the first-ever blog piece for its website.

80
enlightened guests

80 guests enjoyed the Professorial Lecture of Tracey Williamson, Professor of Family Care in November 2019 at Worcester University.

DCC stats and facts

Aug 2019 – July 2020:

263
Support calls offered during lockdown

328
Course registrations on our one and three-day courses during the year

103%
Increase in website visitors: 24,851 (from 12,223 in previous year)

198%
Increase in Facebook likes: 5,110 (from 1,714 in previous year)

52%
Increase in Twitter followers: 1,899 (from 1,250 in previous year)

140%
Increase in Instagram followers: 904 (from 377 in previous year)

177%
Increase in LinkedIn followers: 177 (from 64 in previous year)

(Website and social media increase measured from August 2019 to end of July 2020)

Our course participants statistics so far...

Caring relationship
(Nov 2017 – August 2020)

58%
Caring for a parent

32%
Caring for a spouse/partner

10%
Caring for unspecified friend or relative

We reach across diverse communities: 27% of carers who have attended our courses identify as belonging to a diverse ethnic group other than White British, compared with **19%** of the general population.

Employment status
(June 2018 – August 2020)

32% retired
23% in full-time employment
21% not employed
11% in part-time employment
9% self-employed
2% freelance
2% in education

Living circumstances
(June 2018 – August 2020)

45% do not live with the person they care for
45% do live with the person they care for
10% sometimes live with the person they care for

55 years old
is the average age of course participants so far

Who we are

Trustees during the period of this review:

Amanda Houlihan
(Chair from June 2018)

Catherine A'Bear
Chair of Income Generation Committee

Tony Burch
Services and Research Lead

William Burnand

Alan Cogbill
(retired 28/08/2019)

Richard Drummond

Julie Flower

Darren Garner
Treasurer

David Goodridge
Vice Chair

Lee Marple
Chair of Building Development Committee

Caroline Stevens
(retired 13/02/2020)

Senior leadership team:

Claire Goodchild
Chief Executive Officer

John Misselbrook
Director of Finance

Steve Dubbins
Director of Services

Lara Cooper
Director of Communications & Marketing

Tracey Williamson
Professor of Family Care in Dementia

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

Supporting carers and communities

It has been a productive year for our Services team, with much achieved in a short space of time, under difficult circumstances. Starting the year on the wave of a positive evaluation by the University of Worcester's Association for Dementia Studies, we continued to deliver our successful core course for carers, including a range of new one-day courses.

Our 2020 course programme was our most ambitious yet and set us up to meet more carers through a wider range of course offers. However, COVID-19 forced us to rethink how we could continue to support our carers during lockdown. Undeterred by the complexity of the challenge, our Services team, supported by our Associate Practitioners, quickly developed new and creative ways to reach and support carers during the crisis.

Service team highlights:

The Virtual Carers Centre

The rapid design, build, and launch of our Virtual Carers Centre (VCC) began in March 2020. The VCC hosts a series of thematic portals offering a wide range of information, advice, and self-help-tools for carers.

Themes covered include resilience building, carer-to-carer support, everyday challenges, and carers' rights, with engaging content delivered via videos, podcasts, blogs, and audio recordings. All content is produced by our practitioners, associates, and carers, and we also provide external links to other organisations that can offer valuable support.

Interaction and communication with our external community of Ambassadors and willing family carers have been vital. Their invaluable input has ensured a robust 'carer to carer' virtual space, which continues to go from strength to strength.

While still at a fledgling stage, the VCC is showing enormous development potential and has already resulted in a significant increase in visits to our website. As well as drawing on the expertise of our Ambassadors, we have surveyed carers and drawn support and guidance from our Carers Advisory Panel and alumni. This has helped to ensure we continue to respond to need, provide high-quality content, and expand our future online offers.

> *“The Virtual Carers Centre helped me during the pandemic. I fully recommend it...you have nothing to lose.”*

> You guys at DCC have been so informative and caring, can't thank you enough for our recent chats.

Support calls, online learning, and coaching

In addition to developing online resources, we knew telephone contact would be a critically important source of support for carers during COVID-19. We have developed an in-depth telephone support offer for our alumni and those affected by course cancellations. The calls provide an opportunity to discuss a topic or a situation, validate emotions and experiences, and offer expert advice.

"It's been really good just talking about it."

These calls have not only provided help to individuals, but they have also generated rich insight for us about carers' needs and the challenges faced. This gathering of invaluable information is enabling us to develop more bite-size packages of online learning around practical knowledge and resilience.

Acutely aware that the application of the learning is key to a sustained improvement in wellbeing, we have also developed a follow-up model of one-to-one and group coaching, deliverable online or by telephone. Coaching groups are a key feature of our core course offer, so this was a natural extension of our support through new channels.

"The Virtual Carers Centre is full of useful and relevant information, just right for me. I shall go on dipping into it."

We have tested support calls, online learning, and coaching as bespoke packages with two fantastic charities. Our ongoing work with the Aston Villa Foundation and Connect for Life will only help to develop and strengthen our offering. Sharing their positive experiences of our services and learning as we go, we hope to expand our reach further.

Engaging with communities

Meet Yael Shotts

Community Engagement Officer

We began our engagement programme in July 2019 and I formally accepted the role of Community Engagement Officer in January 2020. As a new role at DCC, it has kept me very busy.

My job is to increase our engagement across the UK with family carers and professionals who can signpost people to our services. I aim to raise awareness and the profile of DCC, whilst working closely with our marketing team and engaging with our wonderful group of Ambassadors.

My first thought was 'Where do I start?!'. However, it soon became clear that what we have to share and offer are both very much sought after. It wasn't long before the opportunities began rolling in.

I have already travelled to Peterborough, Solihull, and Wolverhampton, where groups and communities have a listening ear and a growing interest in what we do.

Our Ambassadors are truly excelling themselves. They have helped us to develop meaningful content for our social media and website by sharing their experiences openly with us. They've written articles and agreed to appear in the media. On a more practical level, Ambassadors help us explore different ways to spread the word about our services.

Lockdown made me reflect on how lucky I am to be in this role. I get to work with a fantastic team of Ambassadors from all over the UK. I work with our Carers Advisory Panel (CAP), with our healthcare professionals, and the broader DCC team. Their collective passion and dedication are admirable and inspiring. What's not to love?

Looking ahead...

I am looking forward to attending and representing DCC at national events and excited about our virtual event in October 2020. I would like to see increasing support for our charity and participation in our services. To achieve this, it is important that we continue to listen, adapt, and be creative in our approach to engaging communities. We also know that professionals appreciate information from us to be able to share with the carers they meet. We would like to increase our engagement with seldom-heard communities and intend to continue making a lasting difference to people who find themselves in a caring role.

Spotlight on an Ambassador

Meet Heather Brown

Heather is a true champion. She cared for her husband who had vascular dementia and now cares for her father who has Alzheimer's.

As our Ambassador she writes blogs for us, has told her story in Closer magazine, and contributes to, shares, and likes our posts on social media. She also helps distribute our leaflets in her community.

Passionate about peer to peer support, Heather also runs a dementia cafe and a monthly carers' group at her local Village Hall, as well as managing a dementia-friendly allotment which was featured on BBC Country File in August 2019.

Not only does Heather take time to support fellow carers, but she also campaigns for them. She has written to her local MP and responded personally, with a full written report, to Warwickshire's Dementia Strategy refresh.

Heather says: *"Becoming an Ambassador for DCC doesn't have to take up much of your time. Not only is it rewarding, but it's also an excellent opportunity to meet other people who are passionate about the same cause, supporting each other and supporting dementia carers".*

Caring and sharing on WhatsApp

Ambassador, Juliet Long and 'The Cheeky Monkeys'

A WhatsApp group which was put together for and by the group who attended our three-day course in July 2018.

We attended our three-day course in July 2018 and set up our WhatsApp group straight after. We called ourselves 'The Chilled Chimps' (inspired by 'The Chimp Paradox' by Professor Steve Peters). Now, two years later and renamed 'The Cheeky Monkeys', we have around ten 'active' members. We were meeting up every few months for drinks and emotion-fuelled weekends at a hotel in Swindon, including a Christmas party, until lockdown when our monthly, virtual parties took over.

We celebrated our second birthday on 4th July, online of course, and we are in touch virtually every day. We'll keep going forever!

The value of the group is inestimable. Bonded by our caring responsibilities and a common understanding and empathy, we can and do talk about anything. As individuals, we have all been through huge life changes. As a group, we have supported each other through job changes, retirements, bureaucracy issues, our health problems, lockdown, one birth as well as the inevitable tragic deaths, funerals, and grief. Even though six of us have now lost those we were caring for, we are still there for each other as we grieve and adjust. And we always will be. Our support for each other ranges from practical caring help, sympathy and support through down days and deaths, to book and hobby suggestions, sharing silly videos and hilarious accounts of people's days that make us all laugh.

It's difficult to distil what our group means to us into words. Different people get different things from the group at different times.

Stef's story

I live in Cotgrave with my husband, Graham. Our sons live close by. One is two doors down and the other is in Derbyshire. They're busy, but help when and however they can. Graham turned 76 during the pandemic and I'm 79. We're both retired now, but we worked as accountants back in the day.

Graham was always happy, laid-back, and full of jokes. He's given me the best life I could have asked for. I'd spend all day in the garden while Graham did the cooking, shopping, and maintenance around the house. All I did was cleaning, reluctantly. When I left it too long and he couldn't stand the mess, he'd help me. My life was easy. I could do what I wanted, go where I wanted, and we had a lovely time together.

I realised there was a problem back in 2015/2016 when we were moving to a new house. Graham did not want to be involved in the paperwork, which was unusual for him as he'd organised everything for our previous moves. We moved a lot, but this time I managed everything. It was so stressful. I don't know how he had coped.

While he used to cook the most delicious meals when we had visitors, he suddenly started to feel hassled if people came over when he was cooking. He would make the same mistakes over and over.

I became impatient because you don't realise what's happening at the time. The kids were cross when they saw me getting irritated with their dad. They're not afraid to call me out when I'm in the wrong. It's hard to hear, but it helps.

Graham's diagnosis was delayed for quite some time as we were in the middle of our house move. We went to three different hospitals and eventually received the news in late 2017, based on a head scan they had taken in 2016.

He didn't understand his diagnosis and I didn't try to explain. I already knew, so it wasn't a shock. In some ways, it's a relief once it's been confirmed, as there are services that you can't access until it is.

Since the diagnosis, he's deteriorated quite a lot. He can't remember which son is which, he forgets their names, and his long-term memory is virtually gone as well.

He needs to be reassured that I wanted to marry him, that I don't regret it, that he's useful. I try my best to make him feel useful. He does the washing up, emptying the dishwasher and cutting the lawn. He apologises all the time for not being able to do things and not being able to help. I don't find it difficult to reassure him because I don't regret it. This could have happened to anybody; it could have been me.

He can't remember any of the good things he used to do. He took up carpentry when he retired and made the most brilliant pieces. He's tried lots of things, but I don't think he ever had much self-confidence.

The services we receive are patchy but at least they're there. Before the pandemic, someone came in once a month to talk to me, the carer. To access this, I had to register with the doctor as a carer. No one at the doctors had suggested I do this, I found out at a dementia group in Nottingham two years down the line.

> *The course helped me to be more patient. I thought the tutors were excellent.*

Your donation means that more people like Stef can access our services at a time when they need them most. Any gift, big or small, makes a massive difference to the lives of family carers.

Our sons are quick to help when I need it. One of them works from home and said he'll move in if anything happens to me. I'm putting the routine of Graham's daily life onto a file on Google Drive, along with details of nursing homes I've investigated. If anything happened to me, I don't think the boys could manage for long and this will give them a place to start.

Finding Dementia Carers Count was brilliant. I didn't think I needed it at the time as I was coping, and Graham wasn't too bad. I was interested though because you never know what you might learn, and it was great. It made me think more about Graham and what was happening to him. I also realised what I was going through. You don't always think about yourself.

The course helped me to be more patient. I thought the tutors were excellent. I kept all the course materials and have found myself referring to them. Speaking to other people helped me recognise that while I wasn't in the best situation, I wasn't in the worst either. That helped put things into perspective.

The experience has boosted my self-confidence. It helps to know that you are doing your best under the circumstances, even if you think you're not. As a carer, you can feel very alone.

My attitude has always been to try things. You just don't know how helpful they will be until you do. On the course, you find that all these people are struggling in the same way you are. There's no need to worry about showing yourself up or saying the wrong thing. You're all in it together.

> *On the course, you find that all these people are struggling in the same way you are. There's no need to worry about showing yourself up or saying the wrong thing. You're all in it together.*

Looking to the future

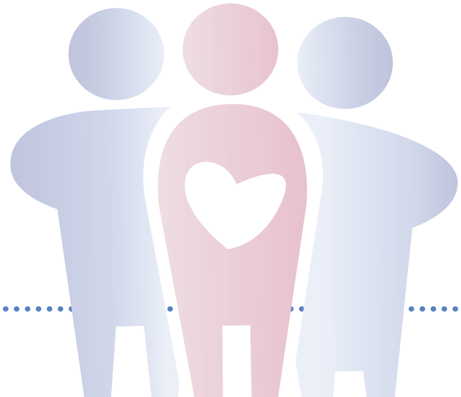
Mankit Yau, Director of Development, shares some insight into DCC's plans for a Dementia Carers Centre.

Q **Can you tell us a bit more about the plans for a dementia centre for carers in the UK?**

A In October 2018, DCC announced the exciting news that it has plans to build a national Dementia Carers Centre. When we started running our courses, we soon realised the huge benefits a centre could bring to our carers and communities. The research carried out on behalf of DCC by the Carers Trust in 2016 confirmed the need, and consultations with carers and professionals cemented the decision to build one. We're delighted to be developing the project. So many of the people we spoke to said they would travel anywhere in the UK to access good quality services a centre can offer.

Our centre will be a place that provides the sanctuary and support carers crave and deserve. It will be somewhere welcoming and dependable, where they can physically go to for expert information, advice, education, and understanding. It will offer a wide range of benefits and services that will improve the health and well-being of carers. We know there are as many as 700,000 family carers of people with dementia in the UK, and this centre will help us to provide the support that's so desperately needed.

After the opening of our flagship centre, we plan to develop further regional centres over the next ten years.



Q **That sounds fantastic and ambitious. What stage are you at right now?**

A A. Much of 2019 was spent searching for a suitable location for the new Dementia Carers Centre. We appointed property consultants to help us find suitable premises and locations to consider. The type of property we looked at ranged from private homes with land for conversion, hotels, and an artisan workshop. After researching 25 buildings, we found the right site. It's located in the West Midlands and we've made an offer. Meanwhile, the support we've had from the local community has been fantastic. The two District Councillors have been very engaged, and the parish council gave us their resounding support. We've also met with local charities and health and care organisations who already support carers of people with dementia. So far, we've been made to feel very welcome.

Q **That IS great news. So, what happens next?**

A The planning permission process is now underway, with a favourable response received after the pre-application meeting with the planning department at the District Council. Our outline planning application was submitted in July 2020, so we must wait until that's processed. We've appointed a project manager who will procure and manage the building process to completion in 2022. The next step will be to appoint an architect who can give us a centre that will be an exemplar showcase for dementia-friendly design to meet the needs of both carers and staff.

Q **Is this the first centre project of its kind for you?**

A Over the past 20 years, I have gained lots of experience in raising funds for major projects in the charity sector. I have helped to build hospitals, clinics, care facilities, research projects, and sports clubs.

I am very lucky to have worked on many interesting projects. The Dementia Carers Centre is a ground-breaking project that will be the first of its kind for this country.

Q **You must be excited. Can you tell us more?**

A Watch this space! This fantastic project will create a significant step-change for dementia carers. Key to our work on this project is drumming up interest and engagement within communities in the region.

Working with support from local communities will also be crucial to its success, as will our supportive and hands-on Ambassadors in the area. We're very much looking forward to reporting more exciting news in the coming months.

> *"I am very lucky to have worked on many interesting projects. The Dementia Carers Centre is a ground-breaking project that will be the first of its kind for this country."*

Financial summary

The Royal Surgical Aid Society

Statement of financial activities

(including income and Expenditure Account)

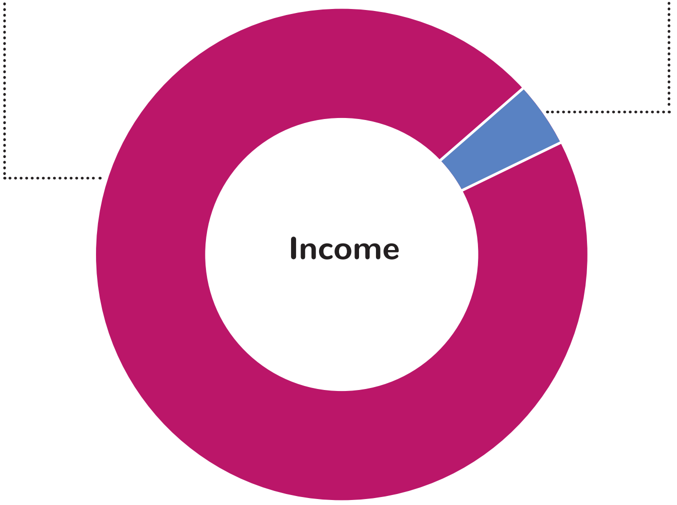
For the year ended 31 December 2019

Total income

£233,000

Investment income
£222,000

Donations and legacies
£11,000

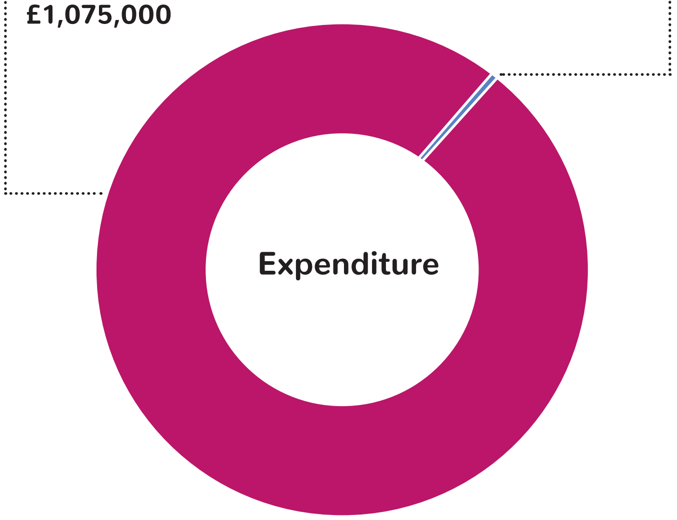


Total expenditure

£1,078,000

Charitable activities:
Service development
£1,075,000

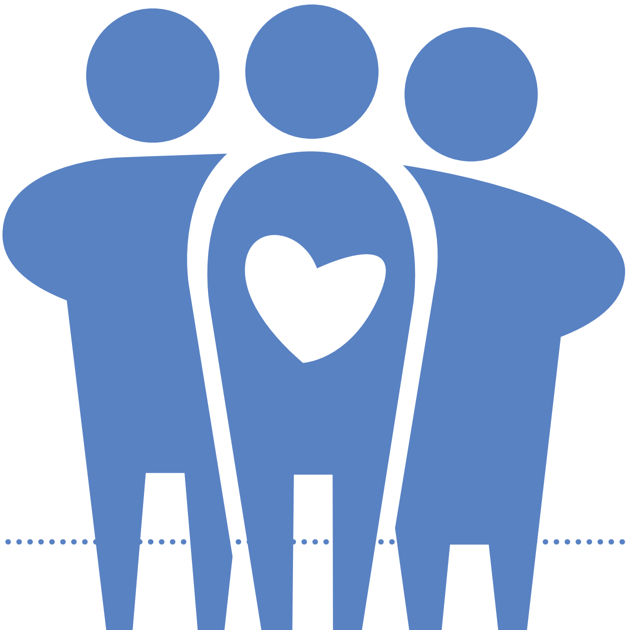
Cost of raising funds
£3,000



Net operating expenditure

£845,000

Building on the development from prior periods, the net expenditure of £845k for the year to 31 December 2019 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

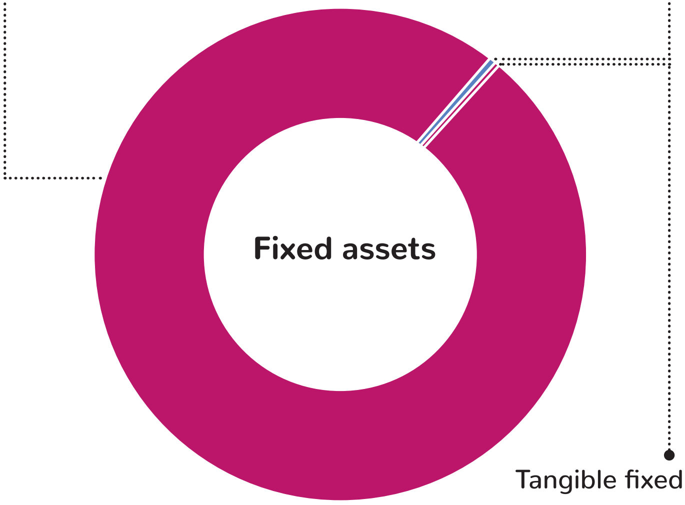
As at 31 December 2019

Fixed assets total

£9,831,000

Investments **£9,774,000**

Intangible fixed assets **£51,000**



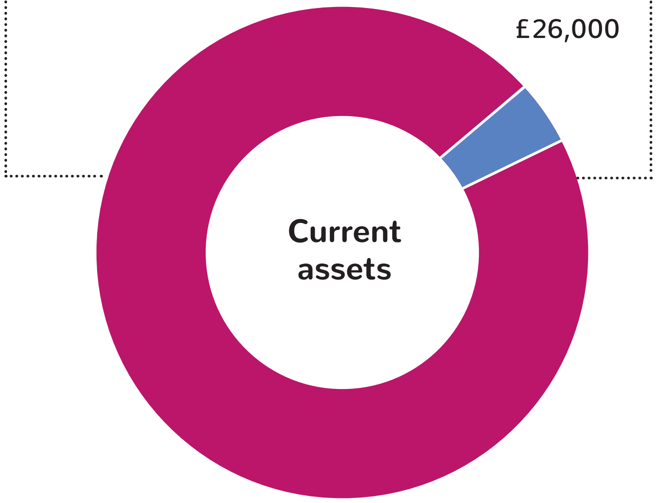
Tangible fixed assets **£6,000**

Current assets total

£494,000

Cash at bank and in hand **£468,000**

Debtors £26,000



Creditors: amounts falling due within one year

£60,000

Net current assets

£434,000

Funds

Unrestricted funds

Designated funds £9,221,000

General fund £1,044,000

Total funds

£10,265,000

The Trustees have committed 40% (£4m) of DCC funds to capital investment in the DCC Centre. The DCC Centre purchase of land, build, and development is expected to cost up to an additional £4m which we are aiming to finance through capital fundraising.

The 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.

Terry’s story

We arrived in southern Spain a week before the UK went into lockdown. We planned to stay there for three months. We normally split our year between Spain and Somerset, but I made the quick decision to come back home. I don’t know when we’ll go back.

Maureen and I have been together for most of our lives. We met at 15, married at 20 and we’ve always lived in Somerset. Before we had children, Maureen worked as a travel agent and I was in retail. When the kids were older, we bought a shop. I foolishly thought I would semi-retire, underestimating how much work goes into running one. We worked there together for about a decade. Then I went into business consultancy and Maureen took a job with social services.

It was then that she first became ill. She started getting severe migraines. The doctor thought they were TIAs (transient ischaemic attacks), not full-blown strokes but enough to immobilise her. After a brain scan in 2003, we discovered 10 unidentified bright spots in her brain. These were calcium build-ups causing intense headaches. Maureen was prescribed medication which completely sedated her. Before this, she had been a fiery, confident person but not anymore. She continued this treatment for years until I insisted on changing GP. Her new physician took her off all medication and she came back to life. However, that’s when we started to notice her memory decline.

She was sent for more scans and diagnosed with Alzheimer’s in 2010. She was 60 at the time.

Maureen had taken medical retirement at 53 because of the migraines, and I was retired by then too. Our plans for the future changed, as I had to be home with her.

> *My daughter saw the course and suggested I go. I found a date that suited and just booked it.*

Without the migraine medication, she has more energy than I’ve ever known her (or anybody) to have. It can be a struggle to keep up with her. In Spain, we go out dancing almost every night. We’ve both loved music all our lives. She doesn’t like me to play it at home anymore, but she still loves dancing. Maureen is the nicest person you’ll ever meet; all she wants to do is help people.

She’s regained her spirit, but she can’t hold a conversation as everything goes over her head. She’s stopped driving and hasn’t cooked for years. If we go to a restaurant, I Google the menu beforehand and try to get her to choose something to eat but I usually end up deciding for her.

That’s how it is in every aspect of our lives. She can’t make the decisions. It never used to be like that. I find it hard that the person I grew up with isn’t there anymore.

Sometimes when we meet people, she’ll recognise their faces but won’t know who they are. She greets everyone like a long-lost friend, with a big hug. People who don’t know her might not be able to tell what’s going on, but we’ve always been very open about Maureen’s dementia. We started a blog to get it out there and let all our friends know.

This has been our lives for 20 years. We have two different lives: one here, with grandchildren and friends, and another in Spain where we’re immersed in the music scene. It keeps me occupied but it’s one of the reasons why I haven’t joined any carers’ groups. I know they would help, but I’ve never wanted to get too involved when we’re always on the move. I haven’t felt I needed it before, but it’s been much harder the last few months. It’s the longest we’ve been home for years.

Your donation can help more people like Terry attend our courses and connect with other family carers. Every donation, no matter the size, makes a big difference to the lives of people caring for someone with dementia.

I've tried to get Maureen to go to a memory café, but as people there tend to be older, she doesn't feel she's like them. If she thinks she's going there to help she's all for it, but she's not happy about me leaving her. I like staying with her, but when I do, she relies on me to do all the talking. In a one-on-one conversation, she will chat but anything more than a group of four and she doesn't say a word.

Maureen doesn't talk to anyone very much anymore as she can't think of what to say. Occasionally I'll get her on the phone to her sister, but she always wants to come off after a few minutes.

At the moment she's experiencing extreme déjà vu. If we go to a new restaurant, she's certain she's been there before. We can't go anywhere she hasn't already been. She has a fictitious friend that takes her to all these places.

Her memory has declined over the past few years, but she's always happy. I'm the one who gets annoyed when things go wrong. I'm not annoyed with her, it's with myself. This is happening more as time goes on.

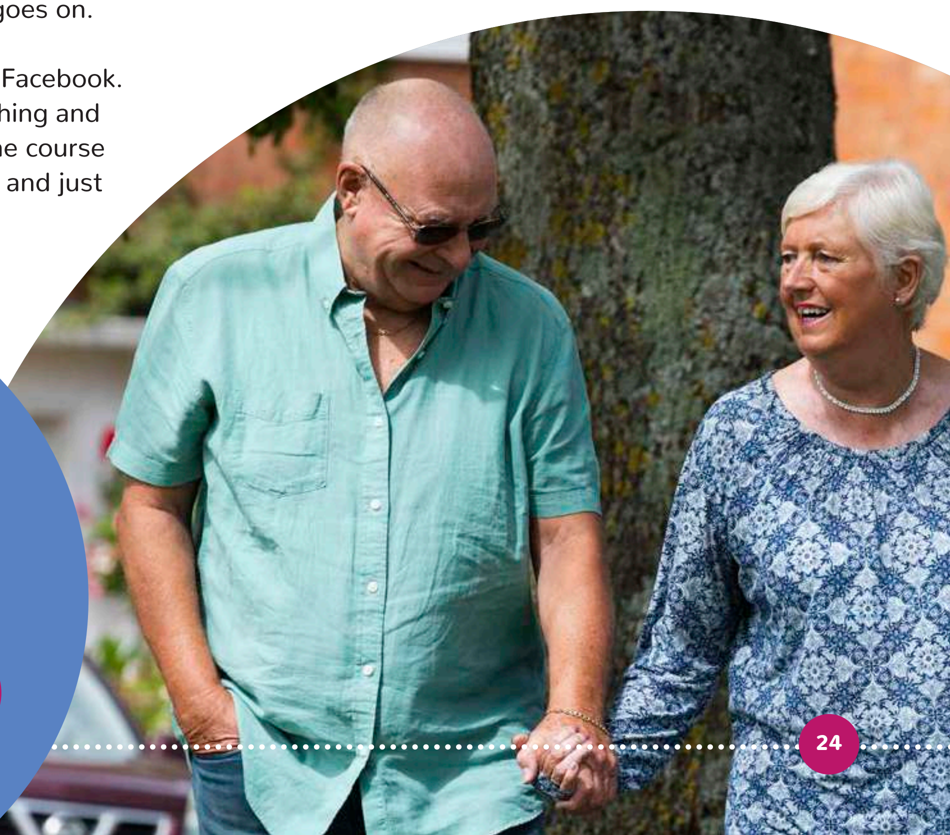
I first heard about Dementia Carers Count on Facebook. You know what it's like, you talk about something and then an ad for it pops up. My daughter saw the course and suggested I go. I found a date that suited and just booked it.

Within minutes of arriving at the hotel, I felt relaxed and was chatting to everyone. There was a lovely atmosphere. Some people were more nervous. For some, it was the first time they'd left the people they care for in years. When you're a carer, your confidence goes a bit. You get out of the habit of doing things for yourself.

The best part was meeting people in a similar situation and getting a glimpse into their lives. There were no airs and graces and no judgement. It helped me a lot. It made me realise that what was happening wasn't my fault and that I had to get over thinking it was. The anger that I felt and the problems I was experiencing were all perfectly normal.

Now I recommend the courses all the time. I even bring leaflets to Spain with me and tell people there. I think anyone in a caring role should go. Get in there and get as involved as you can. Talk to people, listen to people. No-one is judging you. Everyone is there to help you, or to learn.

> “*No-one is judging you. Everyone is there to help you, or to learn. Now I recommend the courses all the time.*”



Closing words from **Claire Goodchild**

In light of the impact that COVID has had on global societies, we decided that the theme for this year's annual review should be 'building communities'. Communities are a feature of our organisation.

Each group of carers that participates in a course forms their own community during the time they are together, and they continue to support each other long after the course ends. Our Carers Advisory Panel is an integral part of our organisation and now our growing number of Ambassadors form our wider community. As a team of employees and trustees, our community is united in our efforts to serve dementia carers.

Throughout lockdown, we held in our thoughts and our daily efforts those families and friends caring for persons with dementia in their own micro-communities. We reached out to as many carers as our small organisation was able to. We did not let up for a moment.

Our last face-to-face carers' course was delivered on 15th March. By that time, some carers were already electing to stay at home whilst others were still risking venturing out to get the education and skills development they so deserve. Two weeks before our lockdown we readied ourselves to change the way we work. Fortunately, as a small organisation, we can be agile. We already had the infrastructure in place to work from home. Within a very short period, each team had a plan of how they would redeploy their energies for the next two months. Little did we know then that it would be six months before we could re-emerge to deliver our courses.

Our Services team was particularly impacted. They switched their strengths from delivering face-to-face courses and developed other ways to use their expert knowledge and understanding of caring and dementia. Immediately we reached out to carers with phone support calls, and soon the Virtual Carers Centre (VCC) was launched on our website. The VCC aimed to impart knowledge to carers in audio recordings, videos, and writing. As we learned more from our carers about what their specific lockdown needs were, we developed our skills for live online teaching and coaching.

We have created new, mutual support communities with partner organisations. We have been able to add value to some of the services local partners provide and begin to consider how we might collaborate further for the benefit of dementia carers.

At the launch of this annual review, we are embarking on our recovery programme. We are sharing learning with other organisations that provide similar services to ours, albeit to different client groups, about how to look forward and get back on track. We are excited to be tentatively resuming our face-to-face one and three-day courses; it is what we do. Due to physical distancing, it is frustrating that we will have to reduce the number of carers we can invite on each course, but the safety of carers and our team is vital. So, to offset those limitations we will keep our online Virtual Carers Centre live and we will be ready to continue with phone calls and live online teaching if necessary.

There was a time before COVID, and there will be a time after COVID. Whilst 2020 is indelibly marked by the global pandemic and our efforts to respond to these very special circumstances, we have continued to look to the long term. Our vision to create the UK's first Dementia Carers Centre remains intact. It is intact not because we are inflexible, but because we know and appreciate more than ever the value of family and friends who care for someone with dementia. We have heard some heart-breaking stories of carers feeling isolated, desperate, and dealing with psychological and practical challenges that many people could not imagine. More than ever we want to create a physical space that represents a community, a place of belonging and of sanctuary. A place where carers are welcome, understood, and where they can drop their shoulders, learn, and be valued.

We thank you for your support.

Claire Goodchild
CEO, Dementia Carers Count

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:

www.dementiacarers.org.uk
☎ Head Office: 020 3096 7894
✉ support@dementiacarers.org.uk

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