



Caring about those caring for someone with dementia

ANNUAL REVIEW

2019



**DEMENTIA
CARERS COUNT**
Supporting Family Carers

Welcome from Amanda Houlihan



I am delighted to share our very first annual review – an extended edition to reflect all our achievements since establishing our new national charity – Dementia Carers Count (DCC). Our name reflects our new purpose of supporting family carers of people with dementia. As well as the financial information, I want to give you an insight into how much we have achieved in these fifteen months.

I couldn't be prouder of the dynamic new team we have built, and indeed continue to build under our CEO Claire Goodchild. Hazel May was appointed as Director of Service Development, bringing with her over 30-years' experience of working in the dementia field as an occupational therapist, writer, trainer and international lecturer. She has already appointed a strong team of professionals to support her, including speech and language therapists, and clinical psychologists, to lead and deliver our courses in which over 300 family carers have already participated.

We have strengthened our executive leadership team with the appointment of John Misselbrook as our Director of Finance, who brings with him 20 years experience of charity finance. We continue to grow awareness of our new charity and have developed a new and contemporary brand under the leadership of our joint Directors of Communication & Marketing, Lara Cooper and Melanie Blanksby.

In June 2018 The Association for Dementia Studies, University of Worcester began their evaluation of the DCC three-day courses. In November 2018 we were delighted to welcome Professor Tracey Williamson as the very first Dementia Carers Count Professor of Family Care in Dementia, based at Worcester University. Tracey's research will investigate the needs of dementia carers providing robust

evidence to underpin carers' experiences, needs and desired outcomes.

Also, in June, we launched our new name and brand and officially became Dementia Carers Count. We wanted to reflect what carers themselves had told us – that they wanted the name of our charity to explicitly state what we were all about. A successful launch event was held in October 2018 at the Royal College of Anaesthetists and over 150 of our carers, people with dementia, academics and supporters attended to hear from Claire and the wider team about our plans to make our vision for family carers a reality over the next few years.

On behalf of the Board, I would like to thank Claire and the team for their enduring dynamism, hard work, and passion to make us the best that we can be, and bringing Dementia Carers Count closer to achieving our vision: that all family carers will feel confident, supported and heard. Most of all thank you to the family carers of people with dementia whom we have the privilege to work with. I continue to be impressed by the strength, humour and resilience that they maintain in the face of extraordinary challenges. They are our inspiration.

Amanda Houlihan,
Chair of the Board of Trustees

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Our vision

All family carers of
people with dementia
will feel confident,
supported and heard.



**DEMENTIA
CARERS COUNT**
Supporting Family Carers



Our mission



We provide a welcoming environment for family carers of people with dementia

to be inspired

to learn

to connect



and receive practical support to feel empowered in their caring role.

We invest in research to understand family carers' experiences, needs and outcomes, and campaign to improve the support they receive.

Our history

In 2012, at the charity's 150th anniversary, our Board of Trustees agreed our future focus should be on supporting family carers of people with dementia. This decision emerged from the findings of a number of commissioned pieces of research to advise on the state of services for our ageing population.

PROVIDING OPERATIONS

The Society's own surgeons begin operating on patients.

EDWARD VII

Edward VII becomes Patron of the Society.

RSAS
Royal Surgical
Aid Society

1862

THE SURGICAL AID

The Surgical Aid Society is founded in London.

1871



1883

FIRST OFFICE

The first branch office opens, in Croydon.

1901



1912

SOCIETY'S GOLDEN JUBILEE

The Society's Golden Jubilee. George V grants Royal title.



**RSAS RENAMED
AGECARE**

RSAS becomes known as AgeCare.



Annual Review
2019



**RSAS'S 150TH
ANNIVERSARY**

RSAS's 150th anniversary brings a change of direction, to support family carers of people with dementia.

2012

**OPENING OF
BRADBURY CENTRE**

Bradbury Centre, AgeCare's first dedicated care home for people with dementia

2001

1995

**RSAS FIRST
HOMES FOR
ELDERLY
RESIDENTS**

RSAS acquires its first homes for older people.

1951



2017

**INTRODUCTION
OF A NEW STAFF
AND STRATEGY**

Experts recruited to create groundbreaking services for dementia carers.

1948

**THE NATIONAL
HEALTH SERVICE**

New National Health Service takes over supply of medical aids.



2018

**DEMENTIA
CARERS
COUNT**

Dementia Carers Count is launched.



**SCHOOL
CHILDREN
SPECTACLES**

Spectacles supplied to children whose families are unable to afford them.



1941



A woman with short, wavy grey hair, wearing a light blue button-down shirt and black pants, is standing and speaking at a long wooden conference table. She is gesturing with her right hand. In the foreground, the table is set with several glass water bottles and microphones. In the background, another woman in a white blazer is visible, smiling. The setting appears to be a professional meeting or conference.

Leadership



Dementia Carers Count is led by the Trustees, Board of Directors and the Carers Advisory Panel (CAP)

Claire Goodchild

Chief Executive Officer

John Misselbrook

Company Secretary

Hazel May

Director of Service Development
(joint)

Gemima Fitzgerald

Director of Service Development
(joint)

Lara Cooper

Director of Communications (joint)

Melanie Blanksby

Director of Communications (joint)

Tracey Williamson

Professor of Family Care in
Dementia

Mankit Yau

Associate Director of Development

Gerald Carew

Director of Income Generation

Trustees during the period of this review:

Amanda Houlihan (Chair from June 2018)

Anna Woda (Chair until June 2018)

Catherine A'Bear

Christine Bailey

Tony Burch

William Burnand

Daniel Carrico

Alan Cogbill

Richard Drummond

Julie Flower

Darren Garner

David Goodridge

Lee Marple

Hugh Risebrow

Caroline Stevens

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

Raydene Carver

Manjit Nijjar

Peter Watson

June Hennell

Jean Tottie

Chris Roberts

Ming Ho

The impact

Two thirds¹ of the cost of dementia is paid by people with dementia and their families, either in unpaid care or in paying for private social care. The impact is debilitating for some carers and unsustainable for the UK social and economic structure. The number of people with dementia in the UK is forecast to increase to over 1 million by 2025¹ and the cost of dementia in the UK is going to rise; with the NHS and social care bearing the burden.

Carers provide **£11.6bn** worth of care each year¹

36%

of carers spend more than 100 hours per week caring for a person with dementia.



£26bn

The current cost of dementia in the UK¹

10%

of carers living in poverty



2/3

people with dementia live at home and most are supported by family carers¹



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

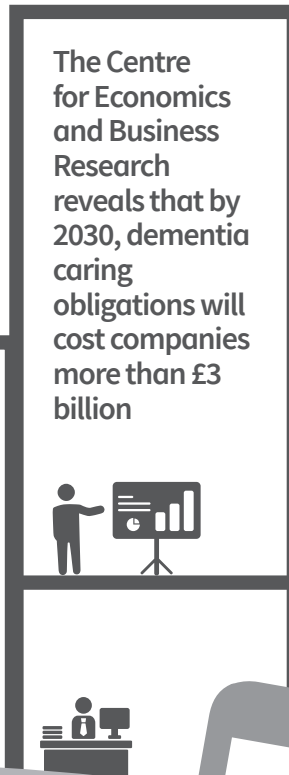
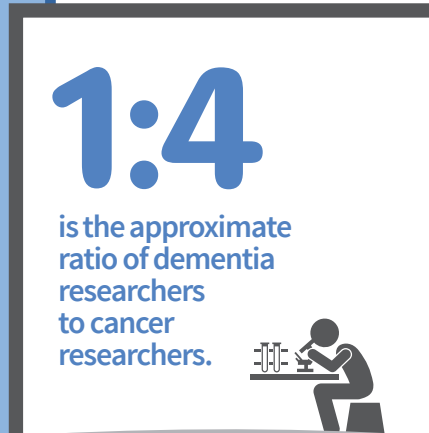
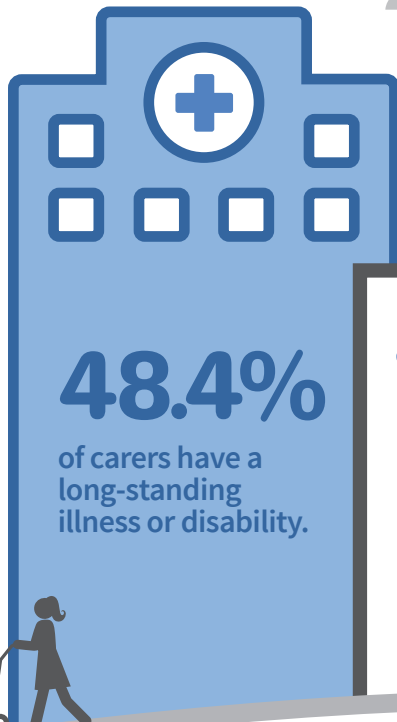




There are

700,000

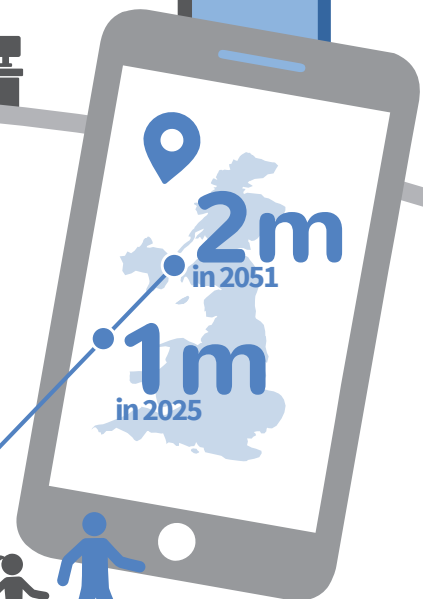
unpaid family carers of people with dementia¹



There are currently
850,000

people with dementia in the UK

and expected to rise to



1. Figures from Alzheimer's Research and Carers Trust 2018.

Mah's story

I live in South East London with my husband. Mum lives in West London and was diagnosed with Alzheimer's five years ago (2014). I used to be a full time lecturer at the London Metropolitan University. I was made redundant which coincided with the time that I knew my mum would need me more.

I knew about a year and half before mum was diagnosed that she had some sort of dementia. My uncle had vascular dementia and I knew what to look out for. I suggested she went for a memory test, but in the end I organised a routine appointment where a memory test was included, as I knew she wouldn't go otherwise. The test suggested that there was nothing wrong with her memory! Once the GP recognised that I had a good sense of what my mother was going through and that I wasn't over emphasising symptoms, it felt more inclusive – rather than me having to prove something was wrong.

I remember I felt pleased that something was happening finally. I'd felt a sense of urgency after the experience with my uncle, and I felt like I was taking some sort of control. Before the diagnosis she was getting anxious and calling me constantly in the middle of the night, and medication has taken that aspect away at least.

Apart from the dementia, she's physically fit. She's still able to live on her own and she currently has a community support nurse who visits her every week for an hour. She also attends a council run day centre three times a week, and a day centre twice a week - both of which she has to pay for. Once a week I travel 2.5 hours each way to stay with her overnight and do all the little things for her that make her more comfortable and allow her to live independently.

As a carer, I currently get no support either financially, practically or emotionally. Being a family carer is 24/7 even when you don't live with the person. It doesn't stop. When I'm not with mum I'm making phone-calls to the council and other services to make sure things happen for her.

Before I went on the DCC course I was tired and exhausted all

the time. I began to have panic attacks – these disappeared after I did the course! I'm a very calm person ordinarily but by the time I went my energy and resilience were at an all-time low.

Preparing to go away was quite stressful – even though I knew things were in place for mum. I went because I knew I'd got to the place where I wasn't coping as well as I had done, and even though it felt strange to go, I knew it was important for me to get some physical and emotional distance. You have to make yourself strong before you can look after others. I didn't tell mum that I was going away – she panics, and you need that head space.

When I arrived at the hotel I felt excited. I'm normally quite a reserved person but I like to meet other people in a similar situation as myself. I was looking forward to it all. To be honest, once you're on the train and it pulls out of the platform – you're already halfway there!

Perhaps the best bit was the breakout group - a lightbulb moment was the fear that I had made the wrong decision about care homes in the past for my Uncle. I realised that I had made the best decision I could have at the time – it was all new to me and I knew nothing back then – it was a baptism of fire. Now I feel I can make good decisions in terms of my mother's care.

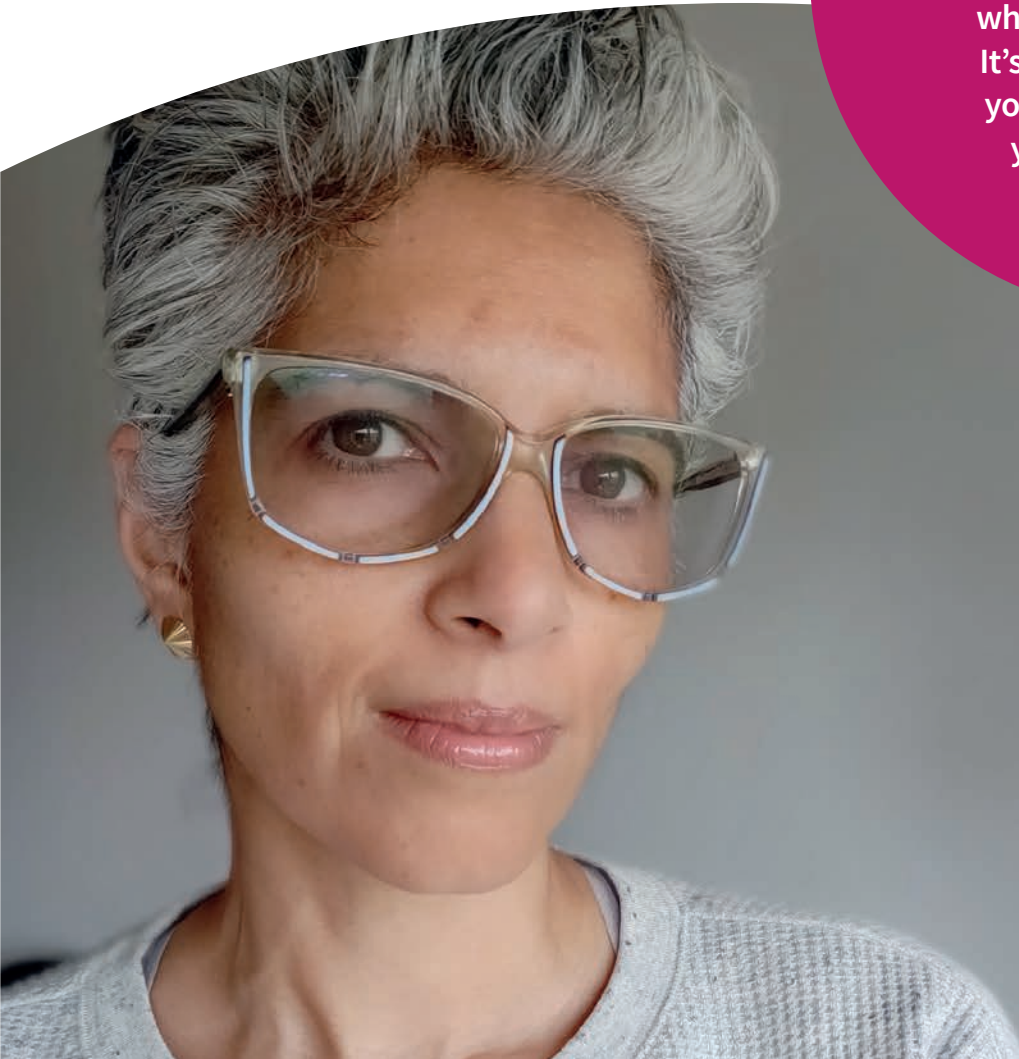
I can honestly say it absolutely changed my life. It's given me the strength to do all the things I need to do. Now my energy and resilience have spiked back to where they were at the beginning of mum's diagnosis six years ago. I have a better understanding of what it's like for mum – why she reacts emotionally rather than rationally.



Some of the course participants now have a WhatsApp group and it's there for support and advice when you need it. It's wonderful to have people who understand the situation you're in.

It's really hard caring for someone – in some respects it's a nightmare, but there are some amazing things about it too. I've learnt so much about myself. I'm much stronger and more assertive. I'd never have chosen this path, but there are points where it can be very rewarding. Just keep doing the best that you can and find those moments of positivity and don't forget them.

“ I would say to anyone considering going on a DCC course to just do it! It's natural to be fearful when you don't know what it's going to be like. It's all about discovering yourself and the person you're looking after. ”



This year's highlights

// We launched our unique services. We proudly stand alongside family carers of people with dementia' //

Claire Goodchild, Chief Executive //

In October 2018 we held our launch event at the Royal College of Anaesthetists. Over 150 people attended, including academics, supporters, people with dementia, as well as our family carers.



Delivering services

We strengthened our Service Development team with the appointment of three Dementia Services Practitioners, including a Clinical Psychology Lead, an Occupational Therapist and a Speech and Language Therapist.

At the heart of our vision is the development of the Dementia Carers Centre. The first of its kind, it will be the 'home' of dementia carers where they can find support, information and understanding. The Centre will also be a hub for research in partnership with the Association for Dementia Services.

We're fundraising to make sure that our Dementia Carers Centre has the best possible facilities and resources for carers.

Our **1st** year

New brand website materials

We have appointed the first Professor of Family Care in Dementia, jointly with the University of Worcester. This demonstrates our commitment to creating a better understanding of the challenges and opportunities a caring role brings.

The Association for Dementia Studies, University of Worcester evaluating the Three-day courses.



Objectives for 2019-2022

Family carers of those living with dementia will be supported to positively transform their experience of caring through our innovative and inspiring services.

The understanding of the experiences and needs of carers is strengthened through research.

Caring for a person with dementia is recognised as important in family life, society and public policy.



Activities



Developing our range of services

We will expand the range of three-day course themes and deliver on our commitment to develop one-day courses focusing on the issues that carers tell us they need more support with.



1

Our aims translate into our 3 core functions

2



Research

Led by Tracey Williamson, DCC Professor of Family Care in Dementia at the Association for Dementia Studies. The programme of research is currently being developed and refined and will focus on family carers' experiences, needs and outcomes.

3



Dementia Carers Centre



Our services and their impact

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

All of our services are currently focused on delivery of our courses, which are run by qualified professionals such as occupational therapists, clinical psychologists and speech and language therapists. If you'd like to better understand your friend or family member, discuss the challenges you're facing and learn about your own wellbeing, we could have just what you need. Among our services are our three-day residential courses, which have been attended by husbands, wives, partners, daughters, sons, daughters-in-law and grandchildren from 18-80 years from across the UK.

Our expert-led support is designed to support a wide range of carers in different situations. Our core residential three-day courses provide an invaluable opportunity for family carers to spend time with experienced professionals, and to have time to talk and share experiences with other carers.

Alongside the core courses are those with more specialist themes – for example, for friends and family either of people with young onset dementia or of those who have moved into a care home. In addition, our 'Caring about...' one day courses offer a more in-depth approach to topics such as eating and drinking, and relationships and feeling secure.

“ The course did me so much good - I am still feeling calm and relaxed ... this is probably the best I've felt in years. It's funny how a few days can be so transformative. ”

Sarah Churchill, Family Carer



I came home rejuvenated, my brain fizzing with ideas for improving communication, taking care of myself, improving resilience. I now understand my husband's behaviour and needs much better and also my reactions.



Kathy Gill, Family Carer



Expert-led

residential courses are co-designed with carers and are evidence-based

Our courses are the only existing service that



ticks all recommendations

in the NICE Dementia Guidelines 2018¹

We focus on building knowledge and resilience



Resilience comes from a sense of belonging, which carers get from being among staff and other carers who really understand what they're going through

Nearly 300 dementia carers

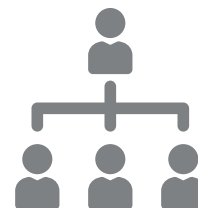
have benefited from our three-day courses



For the first time I've realised I can celebrate what someone with dementia can do, rather than just what they can't.



Professionals working with people with dementia



Working with family carers of people with dementia can discuss their work with us in more detail, so that we can signpost people to us. Together we can support family carers to give them the confidence they need to care for the person that really needs them.

Employers

can ensure that they are doing the best they can for those in their workforce who care for someone with dementia by getting assistance and advice on how to help employees attend our courses.



Laura's
story



Dad was diagnosed with Alzheimer's in April 2014, but we noticed that something was wrong about 6 years before that, although it was very gradual. I moved in with Dad four years after Mum died as I knew he wasn't seeing or talking to anyone else between my daily visits. So, my family and I moved in to be with and look after him.

I gave up my job in Student Services at Cardiff Metropolitan University soon after Dad's diagnosis. It was clear that it was becoming unfair to leave my husband with all the caring as certain factors were making it increasingly difficult. Caring is very isolating and I really miss the contact and everyday conversations with my peers. I find the few weeks that I am able to go to work really uplifting and stimulating, however I still feel guilty leaving my husband to cope. Fortunately, both my daughters help out as much as they can, and a couple of my friends have been really kind and thoughtful and take my Dad out and about too.

Before Dad's illness we had an excellent relationship, and still do although it has changed radically. As his behaviour gradually changed I became the parent, and he the child. But because the changes were so gradual, we took many years before seeking help from the GP, and then to get the referral for the Memory Clinic. Upon diagnosis Dad was prescribed medication that we were told 'may' slow the progress of the dementia. We have to be very careful with his diet - it's been quite a learning curve, we had no training to prepare us for this!

My daughter Jaimee is 29 and her help in caring for my Dad is invaluable. But now we have had wonderful news as Jaimee is expecting her first child in January 2020. My youngest daughter Izzi (20) helps whenever she can too, but she works full time as a Styling Coach, and is also pursuing a career in acting, so she's a very busy lady.

We love Dad dearly, but all our lives have changed radically

due to his dementia and, apart from the Alzheimer's, Dad has excellent physical fitness. I worry that my husband and I will never have much quality time together as a couple and be able to enjoy each other's company as we had hoped - as we have no spontaneity, and very little freedom in our lives. Even if we get a night or two away we are constantly worrying and checking in.

I found out about DCC and went on the course in Swindon with my daughter Jaimee in 2018, leaving Dad with my husband for three days. Although I knew it was going to be a beneficial experience and that all the participants would be in similar situations, I still felt nervous as I've lost a great deal of self-confidence in recent years.

However, the DCC team were wonderful. The course was both informative and enlightening and has really helped our understanding of dementia. This in turn has softened the feelings of frustration and impatience that we as carers can often experience.

One of the highlights of the DCC course was meeting some wonderful people - we drew support from each other and still do. We set up a WhatsApp group and several of us try and meet up a few times a year for meals and overnight stays if possible. Also, learning about what the person with dementia is going through, and what it feels like for them, has totally transformed my way of thinking. The fact that there is an organisation like DCC that 'cares about the carers' was most unexpected and so very welcome. I genuinely cannot recommend these courses highly enough to anyone who is coping with caring for a loved one with any form of dementia.

Thank you to all who are connected to DCC, you have helped my family considerably and we will continue to 'pay it forward' and try to help others in similar situations in any way we can.

Interview with

Hazel May

Director of Service Development

Q Can you tell us about your career as an occupational therapist? Why did you decide to work with people living with dementia and their families?

A My career has been an absolute joy! I've loved every moment. I went on a course to find out about jobs in the NHS and discovered occupational therapy. I immediately knew it was the perfect choice for me – a mixture of arts and science. My first job was at an inpatient mental health assessment centre for elderly people with dementia. I fell in love with the work. I've always had a good relationship with older people – particularly my grandmother who was my confidante. It's an incredibly complex field – older people with dementia have a lot of needs, not just mentally or physically, but emotionally, with balance and eating and so on. I decided to specialise in dementia. Understanding dementia is to understand what it is to be a human being – all the frills are peeled back - it's very raw, very real when you speak to someone with dementia.

Q What are the biggest changes in health and social care that you would like to see for family carers?

A I think I would like to see more recognition, support and information for family carers. Government policy should show leadership on this issue. And then I would like to see two more things! First, much

easier access to services – that comes from good information. For example, I met a carer recently whose spouse has been diagnosed with Lewy body dementia and no one, at any point has told her that there is an organisation set up with information just for her. Secondly, I would like to see dementia de-medicalised with more emphasis on and understanding about adapting to people's changing needs.

Q Tell us why supporting and working with family carers of people with dementia is so important right now?

A It's becoming increasingly important – 1 in 3 people will care for someone with dementia in their lifetime. Rates of depression are higher for carers – we need to keep their resilience afloat. The cost of not supporting family carers is huge!

Q How did you first become involved with RSAS/DCC?

A My first involvement with RSAS was four years ago when I was invited to an expert working group to explore what their family carer services should look like. RSAS wanted to consult with experts in the dementia care sector about a resource centre for family carers. I came away feeling really happy to hear it was happening. I was semi-retired and the



I would like to see dementia de-medicalised with more emphasis on and understanding about adapting to people's changing needs.

Hazel May, Director of Service Development



job description for my role dropped into my LinkedIn with a day left to apply! I thought that I just had to apply – I knew what the current situation was for people and their families with dementia. It wasn't right and tended to be traumatic for everyone. I used to fantasise about having my own centre to support family carers where I would take a different approach – if I won the lottery that is what I would do! To be honest it felt like I'd won the lottery when I got this job.



Can you tell us how a family carer might typically feel before coming on one of our courses? And after?



We really get to know them over the three days - they tell us lots about how they are feeling. They tell us our courses are like a sanctuary – it's often the first time they've had time and space for themselves. Some are run down, worn out...

some have lost the sense of who they are. They're all nervous. They're worried they've made a big mistake in coming. We try and build relationships with them before they come, and tell them what to expect and answer any questions they may have. We've handpicked the hotel so the staff are very kind caring and flexible. We want our carers to feel safe, comfortable and supported. We generally see a transformation – we've had carers who come out of their shells, literally dropping their shoulders and relaxing. They've made friends. They're in a more hopeful place.



It's becoming increasingly important – 1 in 3 people will care for someone with dementia in their lifetime.



Q You lead many of our core and one-day courses – what have been the stand out/ proudest moments for you?

A The best moments are always when we see good things happening to our carers. For example, dementia being explained in a way they understand for the first time. I'm also proud of the team we've built. The team didn't know each other before – we're brand new. Carers tell us that they feel like we've been working together for years. We also have fun! But, because we are experts I'm proud that we have the best possible team. We really value them. We've got a great mix of psychology, speech and language therapy, occupational therapy etc – it's wonderful to see – they're like an orchestra in the way they work together.

Q What are your plans for the coming year?

A We're appointing associate practitioners to support the in-house team so we can respond to increased demand for our services. Also, we're developing a suite of one day courses, our Caring About series, which we are rolling out. With more one day courses in development.

Q What do you do to relax outside of DCC?

A I do like my own space. I've raised my family so I've stopped plate spinning the family and the career. The demands on my time are less – being free to do my job well and enjoy it is my wellbeing. I do recharge by being on my own – I love to binge watch Netflix and I enjoy knitting! I also have dogs and a husband! I look forward to our extended family holiday in Cornwall every year.

Q What would you say to a family carer who was unsure about attending a DCC course?

A If you come on one of our courses it will be worth it. 300 carers have told us that they get rest and headspace, and make bonds with other carers. And they learn a lot. You will be in safe hands and you will be at the top of our list the entire time. We are here for family carers. We have no other agenda.



The best moments are always when we see good things happening to our carers.





Our research


Our offering has been developed based on evidence from thorough research commissioned from independent sources, such as universities, into carers' needs and the effectiveness of services currently available to them.

We've created a specialist research unit to investigate carers' needs, experiences and outcomes.

In partnership with the Association for Dementia Studies, University of Worcester, Professor Tracey Williamson is the first specialist DCC Professor of Family Care in Dementia. We'll use the evidence from our research unit to constantly improve support for carers and help other services develop evidence based for the support they offer.



I am delighted to be joining the partnership between Dementia Carers Count and the Association of Dementia Studies and expect my involvement will further cement the excellent work between these organisations.

Recent years have seen a number of initiatives that have helped enhance family carers' experiences, with many of these being led by staff and partners of the Association for Dementia Studies and, most recently, DCC's new ground-breaking services for dementia carers. There is still much work to do to create better understanding of the challenges and opportunities a caring role brings and to identify ways of helping carers to feel more supported, empowered and resilient. I look forward to being a part of it. 

Tracey Williamson, Dementia Carers Count Professor of Family Care in Dementia



Gill's story

We live in South London and have two grown-up sons. Paul was a fine art dealer at an auction house and I was working at the Museum of London. We were planning our future together – thinking about Paul retiring. We always wanted to travel around India.

I first noticed that something was wrong when we took part in a 100km charity walk to Brighton for Parkinson's Disease. It was weird that Paul didn't seem to be making the effort to train for the event – he did no practice – it just hadn't dawned on him that this was something that we needed to prepare for.

At that time, he was working all hours but not getting things done – which wasn't like him at all. His perception of all this was that he was just bored – he wanted to give it all up and do something else – he was like a different person. Things at work became progressively worse. He went to his GP and they diagnosed stress and a “mid-life crisis”. They even did a memory test, which he passed - but to be honest, it's easy to pass.

We went back to the GP and there was a three-month waiting list to see a psychiatrist, so we decided to go to a private psychiatrist who diagnosed “masked depression”. The thing was that Paul was as happy as anything! He was prescribed SSRI's, which didn't work. So, the dose was increased. I wasn't convinced by the diagnosis so we managed to get an NHS review and they said to up the dose again. I still wasn't convinced – I was hopping mad and asked for a brain scan. His future depended on getting a diagnosis. I finally managed to get him to the memory clinic and asked for an MRI.

A full year after he'd had to stop work through illness, he was diagnosed with young-onset dementia. We were told we were actually “lucky” that he had such an early diagnosis but there was nothing really we could do, despite Paul's condition being life limiting and life shortening.

I, of course, did some research on the internet and read that early-onset dementia was horrendous. I know you shouldn't do that – but we had no information! I felt desperate and I was advised by a medical friend to get a second opinion; we managed to get a referral to the National Hospital for Neurology and Neurosurgery. They confirmed that it was

indeed early-onset dementia and that it was the cruellest form of dementia. They told me that I should hope for the best and prepare for the worst.

When you first get the diagnosis you go through shock, then it's like a bereavement. After you deal with all of that, only then can you start looking for help. It takes time for you to be in the right place mentally and emotionally.

I first found out about Dementia Carers Count by sheer chance through a friend. She sent me a link to their website and information about their courses, and I thought I had nothing to lose! Hazel May, Director of Service Development contacted me and I made arrangements to go on the course in May 2018.

When I first arrived at the hotel, I knew that I needed this! I had no support at home outside of immediate family and some local support group meetings that I attended. All the support I have, I've had to seek out and get for myself – so the DCC course was literally a lifeline for me!

On arrival, I was exhausted and in a flap! I had to drive there, and I wasn't used to it as Paul used to do all the driving. I even did an advanced driving course after he was diagnosed just to help me get back in the car. My mindset was very much “well it can't do any harm to go” and I admit, I was quite sceptical at first.

I met other family carers who were living with different conditions to Paul – and I thought this is not for me! I was wrong.

It was such an eye-opener to see how other people had common problems, despite living with different diagnoses.

I can honestly say it was an emotional rollercoaster throughout the three days – I learnt so much. Suddenly things clicked into place. I had an understanding of dementia, which I had never had. Things like breathing exercises and mindfulness were incredibly useful, but for me, the best bit was that I got to understand the disease a lot better. You never get this explanation from the doctors.

Gemima taught us resilience. That can never be underestimated. People tell you all the time that you're amazing – but what choice do you have? The course didn't just take care of our emotional wellbeing, it was also practical. It was this practical side that was particularly invaluable to me. Being told that "you CAN do this. You WILL get through it" meant so much. It also made me realise that I should find help from other sources. I thought there was nothing for me, but I now know that there are lots of people out there who are selfless and will volunteer their time to run support groups. Since the DCC course, we've now got someone who volunteers to take Paul out for two hours a week so I can have a break.

Dementia has never been in our family - you suddenly realise that there are an awful lot of people needed to pick up the slack in our services. Being a carer is like a prison sentence. It's very isolating - friends and family withdraw as they don't know what to say. They don't know how to handle it –

they'd rather not have to say anything. It shouldn't be locked away from society like it's a taboo subject – people with dementia are often treated like pariahs!

When I see other people who are newly diagnosed I immediately think that they could benefit so much from someone guiding them through it like the DCC course did for me. I want to tell them what I learnt - that they shouldn't beat themselves up about shouting and screaming in frustration. Everyone is human and everyone is different.

As long as the person you're caring for is happy – we all react very differently, and that's ok. I'm sure people around me had very different opinions on how I was coping, but that doesn't matter

On the course, you learn how to care - how to actually be a carer. Up to then I was doing the very best that I could, but the course has taught me so much about dementia – now I can be better.



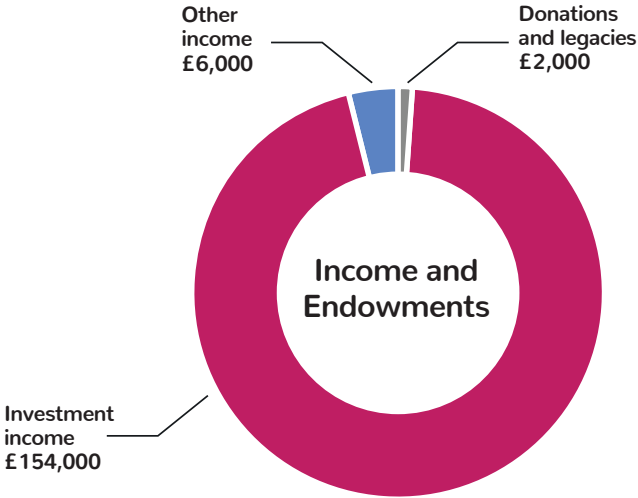
Financial Summary

The Royal Surgical Aid Society Statement of Financial Activities

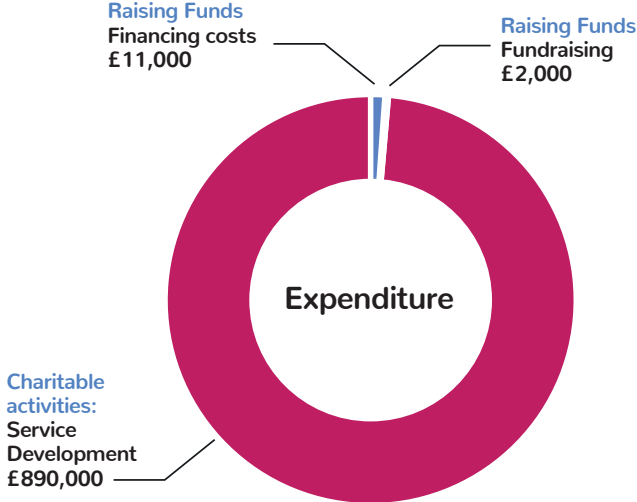
(including the Income and Expenditure Account)

For the 15 months to 31 December 2018

Total Income
£162,000



Total Expenditure
£903,000



Net Operating Expenditure
£741,000

Building on the strategic and planned financing from earlier periods, the net expenditure of c.£1m in the 15 months to 31 December 2018 represents a continuing and significant investment in building and developing the service model and organisational infrastructure necessary for the future delivery of our mission.



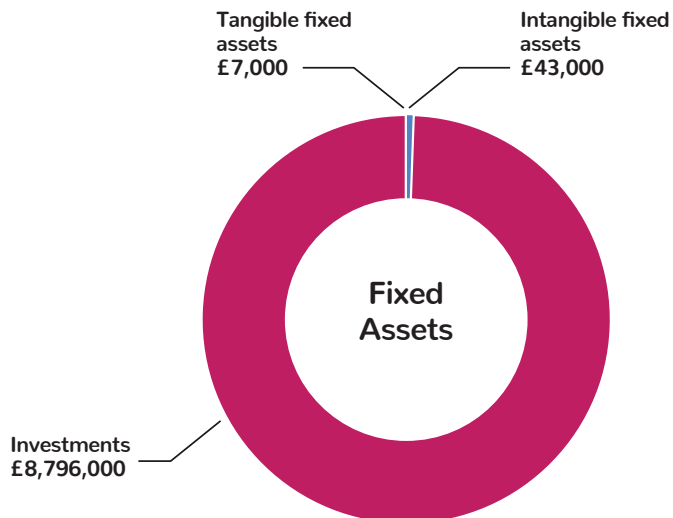


The Royal Surgical Aid Society Balance Sheet

As at 31 December 2018

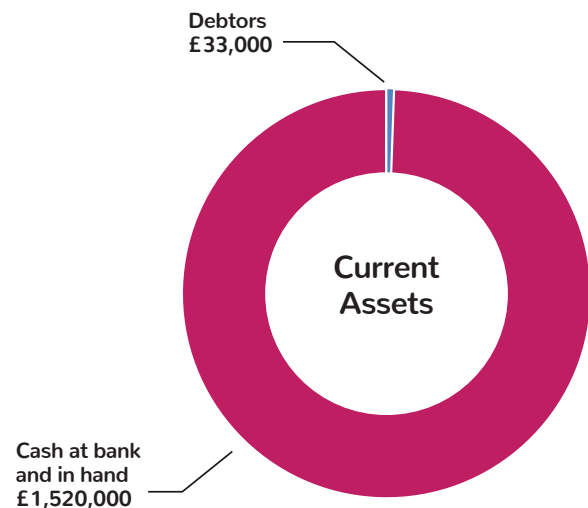
Fixed Assets Total

£8,846,000



Current Assets Total

£1,553,000



Creditors: Amounts falling due within one year

£56,000

Net Current Assets

£1,497,000

Funds

Unrestricted funds:

Designated funds £9,403,000

General fund £940,000

Total Funds

£10,343,000

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 an additional £2m 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.

Future investment in our services

Continuing to build on the planned strategic investment from earlier periods, the net expenditure of c.£1m in the 15 months to 31 December 2018 represents further significant financial commitment in building and developing the service model and organisational infrastructure necessary for the future delivery of our mission.

With our service delivery now very much formulated and tested through the delivery of pilot courses directly to carers of people with dementia, Dementia Carers Count is ready to move to the next stage of establishing a Centre devoted to the delivery of these services.

The Dementia Carers Centre will be a design and build 20 bedroom hotel-style facility through which we can ensure we fully provide for meeting the needs of our carers. We have identified that the location for this Centre, providing the most ideal transport facilities for carers across the UK, will be in the Midlands, and

The Trustees have committed to investing up to £4m of DCC funds to establish the Dementia Carers Centre. The balance of the funds required for this project will be raised through a capital fundraising campaign. The remaining reserves will be utilised in the continued development of a sustainable model, and then residual funds, together with income from service delivery and operational fundraising, will be at a level sufficient for the ongoing delivery of our objectives.

Dementia Carers Count is in the process of investing in land in this area for that purpose. Dementia Carers Centre have a professional team currently working on the optimum Centre design to provide the best facilities both for the carer and for the person with dementia. A focused capital fundraising campaign will raise external investment to enable us to build the Centre.

The expectation is that this Centre will be completed for the delivery of services from 2022, with a three year period for establishing the service delivery at full capacity from 2024. Initial service delivery is expected to be provision of Dementia Carers Centre one-day and three-day courses, carer coaching and carer counselling. Once the Centre has been fully established, the next phase will be to evaluate the feasibility of rolling out these services through regional hubs.

We are looking forward to our investors and other stakeholders joining us on this journey.



**Purchase, design,
build and establish
the UK's first
Dementia Carers
Centre**

**Provide capital
financing of up to**

£4m

from DCC reserves, the
additional requisite funds
to be generated through
fundraising

**Provide DCC Services
from the Centre with
effect from**

**January
2022**

building to maximum
expected delivery
of 90% of service
capacity by 2024

**Focus DCC Services on
the provision of DCC**

**one-day and
three-day courses**

with potential future
development of carer
coaching, carer counselling
and carer support plans

**Provide DCC Services
exclusively through**

provision

at the Centre, with any
potential future delivery
through regional hubs

**Build our reputation
as the 'go to' place for
dementia carers and any
member of the public,
the media and policy
developers wanting
to know about the
experiences, needs
and desired outcomes
of dementia carers**



Plans for the future

Dementia Carers Centre

Our services are currently delivered from several venues around Birmingham and the West of England, but our future Dementia Carers Centre is at the heart of our vision.

The Centre will be a place where everyone will understand and empathise with what carers are going through; where they can drop their shoulders and relax whilst learning and re-charging their batteries. We'll start with one flagship Centre and plan to develop more regional centres over the next ten years.

We're fundraising to make sure that our Dementia Carers Centre has the best possible facilities and resources for carers. If you are able to help in any way, please get in touch at fundraising@dementiacarers.org.uk or go to www.dementiacarers.org.uk/get-involved/ to see how you could get involved with our Dementia Carers Centre.



**A safe space,
a sanctuary, a
haven**



**Quality of
care**



**State-of-the-art
technology**



**Purpose
built**



- We are currently planning our flagship Dementia Carers Centre; the 'home' of family dementia carers
- It will be a safe space, a sanctuary, a haven
- It will be funded through the legacy from our previous charity (AgeCare) but will require ongoing fundraising to be sustainable for the long term
- Following the opening of our flagship Centre, further regional centres will be developed over the next ten years





Why support us

Dementia Carers Count needs your support so we can continue to deliver the best possible services to our family carers.

There are many ways by which you can help us achieve our vision of a place that fully understands carers and the lives of people with dementia. We want to create the 'home of dementia carers' in the UK. We are going to build a national resource centre to open in 2021, and we are actively fundraising to ensure that the Dementia Carers Centre has the best possible facilities and resources.

// What a super course, group and trainers. Really enjoyed their company. Have needed to breathe on my return to reality! **Much better option than getting cross.**

Gil Brown, Family Carer





Please support us

We're dependent on your support and there are many valuable and essential ways you can help us.

Donations



A donation of any size makes a massive difference to the lives of people supporting loved ones with dementia. Your donation will ensure that more family carers of people with dementia can access our services when they need them most.

Participate in or organise fundraising events



Hosting a fundraising event for Dementia Carers Count will help us spread the word about the valuable work family carers do and raise the funds we need to reach our goal. This will ensure that no one caring for a loved one with dementia goes without the support they need.

Pledge a legacy



Leaving a gift to Dementia Carers Count in your will will help to build a brighter, more caring future for family carers of people with dementia.

Become a benefactor



We invite you to consider making a philanthropic gift to Dementia Carers Count that will enrich the lives of dementia carers and make sure they have the support they need to do the indispensable work they do.

Contact us by email:
fundraising@dementiacarers.org.uk

Become an ambassador



As a Dementia Carers Count Ambassador, you'll be helping to ensure that family carers of people with dementia know about and can access our services, at a time when they most need support.

We need people who can represent DCC in their community and beyond to help to spread the word about our courses and our new services and who can make sure that anyone looking after a person with dementia knows about our courses.

amazon smile



Dementia Carers Count is a registered charity on AmazonSmile at the charity arm of [Amazon.co.uk](https://www.amazon.co.uk). Amazon Smile is a simple and automatic way for you to support Dementia Carers Count every time you shop, at no cost to you.

Visit at smile.amazon.co.uk



Working with health and care professionals

Our courses for family carers are designed specifically for family and friends or people with dementia, however we do understand that sometimes attending as a professional can be useful.

It will enable you to recommend our courses to family and friends of people with dementia whom you support, and to find out more about how carers feel about the issues that they face with different types of dementia

Our expert Service Development team is also available to work with other healthcare professionals on specific issues such as eating and drinking, occupational therapy and clinical psychology.

Working with businesses

We work in partnership with companies to create lasting change and ensure that everyone in the community has the support they need.



Becoming a supporter and partnering with Dementia Carers Count will bring lasting benefits to your organisation. Whether you're looking to engage employees and customers in a unique way or strengthen brand awareness and purpose, we'll work with you to ensure your partnership with us achieves shared value and impact.

Brand awareness

Our supporter opportunities provide:

- presence on the Dementia Carers Count website and social media
- flexible, tailored sponsorship packages
- positive brand association



Employee engagement

Supporting us will help:

- demonstrate to your employees, customers and potential customers your company's commitment to an issue that affects lives every day
- boost staff morale
- generate positive PR opportunities



Support Dementia Carers Count now
020 3096 7894

info@dementiacarers.org.uk dementiacarers.org.uk



Message from the Chief Executive, Claire Goodchild



When I look back at all we have achieved, I am humbled by the work of my new team and I can't help but be proud, not just about how much we have physically delivered, but also how the team has knitted together to form a strong and dynamic unit.

We've welcomed over 300 family carers through our doors, and I will never tire of seeing their shoulders drop as if a huge weight has been lifted – often it's the first time in years they've had for themselves or to meet other people in a similar situation. I'm moved by their resilience and dedication in living with a situation that no-one would ever choose to be in.

We want to ensure that we can offer help to family carers wherever they are in the UK. Geography should not exclude anyone from accessing expert-led support and information. It's therefore with great excitement that I can say 2019 will bring us even closer to building our Dementia Carers Centre, which will be the 'home of dementia carers' in the UK. We want to make our Centre accessible to as many carers as possible and so we've been researching potential sites around Birmingham and should be in a position to purchase the land by the middle of the year.

In 2019 we plan to establish our Fundraising and Income Generation directorate as well as further recruitment to our Service Development department. The priority for our new Fundraising team will be to forge partnerships and deliver a capital appeal to raise the funds to enable us to build our Centre over the next two years and to ensure our financial sustainability to deliver our services to as many carers as we can reach.

We feel passionately that family carers of people with dementia deserve evidence-based services and support from qualified professionals. Our services so far have drawn on existing evidence and we always gather feedback from carers. We look forward with great anticipation to the receiving the results of the evaluation of our three-day courses conducted by the Association for Dementia Studies - we are on track to receive the interim findings in May, and we will publish the full results in September 2019.

We are also celebrating the fact that our 3-day courses are currently the only intervention for carers which hits almost all of the National Institute for Health and Care Excellence

(NICE) Clinical Guidelines. In January 2018 NICE published a draft Clinical Guideline consultation paper, "Dementia; Assessment management and support for people living with dementia and their carers", outlining methods, evidence and recommendations. NICE advises that carer interventions are likely to be most effective when provided as group sessions and recommends that carers of people living with dementia should be offered a psychoeducation and skills training intervention – all of which is offered to family carers attending our three-day courses. This is a fantastic achievement in our first year and shows that we are committed to delivering the very highest standards for our family carers.

Alongside this, the Service Development team and I have spent a great deal of time evaluating our current service options, and we have listened to feedback from our family carers to develop a new range of one-day courses. They will offer a focused, in-depth but digestible approach, covering specific subjects that carers have told us they want more information on. This will help build their skills and confidence to see them through the challenges that caring can bring. This way, we hope that we can reach even more family carers across the UK. We plan to launch the new courses early in the summer of 2019.

I continue to be enormously proud of the vision that we are making a reality. The energy, enthusiasm and time that our supporters give us enhances our work immeasurably. Our Carers Advisory Panel is outstanding. They have described working with us as like being part of a family.

It has been a joy to create the Dementia Carers Count team; each and every member is professional and dedicated to bringing the very best to family carers. It was our Trustees who set us on this path, and we are proud to be realising their vision. I want to thank you all for travelling on this journey with us.

Claire Goodchild, Chief Executive

ANNUAL REVIEW

2019

Being a carer is a demanding role, and is a situation nobody chooses to be in. Carers often ignore their own needs and focus on the person with dementia.

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



7-14 Great Dover Street
London SE1 4YR
info@dementiacarers.org.uk
020 3096 7894



**DEMENTIA
CARERS COUNT**
Supporting Family Carers

dementiacarers.org.uk

Charity registered in England No. 216613