

Case studies and quotes from carers

Digital Resource for Carers

"The course helped me become aware of other issues often overlooked, ignored or taken for granted." Julie, carer

"Doing things online saves me time as a carer. It's a no-brainer and makes sense to me." Lucy, carer

"It's one of those situations where you don't realise how useful something is until you don't have it." Simon, carer

"It is well put together, easy to read without being patronising, and gives me hope, understanding and reinforcement of me as a person, not just a carer." Carer

"It made me think about working again. I have been thinking about returning to work but I am thinking that nobody will employ me. The course made me think that it could be a possibility." Carer

What carers tell us

In caring for someone you can get very lost. The About Me course helps you to stop and think, shows how to lay things out, and calm down.

Really enjoyed doing the course. Thank you Carers UK!

I think Jointly is a great idea as we use self directed support and this app is a great way of sharing information with the people I choose. What if something happens to me then everything being in my head is no good to anyone. This app will enable me to keep everyone in the loop. Thank you!

I'm a junior doctor who has just started using your excellent app Jointly for the care of my grandfather, and it's been a really useful tool.

I really enjoyed doing the About Me course. It is excellent and I would do it again in another year if I could as you forget things.

Jointly is an excellent way of keeping everything in one location that can be accessed in real-time by those who need to have access. It saves time ringing round or texting each other to keep up to date.

Valuable way for families to keep connected over joint care of a relative. I'm a hospice senior nurse and advocate it's use. Thank you for creating it.

Upfront gave us an invaluable summary of what support we are entitled to and what else could help our circumstances.

Very helpful app, especially the ability to access data offline.

Jointly

"I think it's a great idea as we use self directed support and this app is a great way of sharing information with the people I choose. What if something happens to me then everything being in my head is no good to anyone. This app will enable me to keep everyone in the loop. Thank you!" Agnes, carer

"Our family's intensively used Jointly app to care for my uncle. Sadly my uncle died in March but the app enabled us to support him to die at home, in line with his wishes." Denise, carer

"Jointly has given me the confidence to be able to give good support at any time, including at a time of crisis and has helped me to stay on top of things and allowed me to access information, including medication anytime, anywhere." Kate, carer

"Jointly has been fantastic for supporting my daughter who has Down's and lives independently. Thank you so much for it – I have been recommending it widely!" Liz, carer

"I started using the Jointly app last year as I thought it was a great tool and solution for the poor communication between the care staff and us for my son's supported living. It was a struggle to convince the care staff and managers to take up the app. But once I convinced a care staff to join the circle, they took it on and can see the positives of transparent communication. So I just wanted to let you know we think it's a great app." Hong, carer

"Jointly has been an absolutely brilliant way for us as a family to co-ordinate all care arrangements – Thanks!" Judith, carer

Testimonials from organisations

"There's nothing worse than hearing a stressed carer saying "if I had known about that earlier, then the last few years would not have been so difficult". Without the right information at the right time carers find it hard to make informed decisions. Digital information can be accessed anytime anywhere by an increasing number of people to help support decision making."

"There are a lot of apps and online information available but few deliver all that they promise. The Digital Resource for Carers does what it promises. It is easy to use, well-written and offers access to a wide range of information, advice and support in one place which can help those who care and those who support them."

"We feel Jointly is an innovative product we can offer carers in order to support them in their caring role. It is especially useful for those who are juggling work with care and those carers who are sharing care with other family members, friends or neighbours."

"As budgets get tighter we need to work smarter in reaching out to carers. The Digital Resource for Carers provides a brilliantly cost effective way of doing this."

"Digital is a way to share information with a large audience 24/7 across a wide geographical area in a format many people find easy to access."

Very positive response. Users liked the app and new carers found Upfront very useful. The About Me course was also cited for being practical."

Jointly case studies

Olga's story

"When I first heard about Carers UK's Jointly app, I was juggling full-time work with caring for my parents.

I was living in London – 170 miles away from their home in Staffordshire. It was a complicated and stressful situation. My mum has a range of conditions, including osteoporosis and arthritis. My dad had been caring for her, until he was diagnosed with lymphoma and needed care himself.

My siblings and I tried to coordinate it between us, taking turns to travel to their home to help around the house, cook meals and take them to appointments.

Jointly was an excellent way of making sure we had all the information we needed in one place. We only had to enter the information once and all of us had access to it. Up until then we'd been trying to coordinate everything through email, phone calls and trying to share calendars.

Each time one of us took mum or dad to an appointment we would make notes in Jointly. The medication list meant we all had up-to-date information to share with the GP – which was essential when dad was prescribed aspirin, which he wasn't allowed to have whilst on his cancer drugs.

Being able to look after my parents has been really important to me. I wanted to return the care and love they gave me during my childhood. After dad passed away, my siblings and I have continued to share the care for mum, and Jointly helps us do that"

Kate's story

Kate has been a carer for a long time. In the past she cared for her husband and mum and she is now helping out her elderly friend. She has been using Jointly to help co-ordinate care. We asked her to share with us her story and her view on the role technology can play in caring for a loved one.

"I cared for my late husband over a period of more than 25 years. I can honestly say that for the first 20 years, I did not see myself as a carer, I was just a wife and a mum. Not until I reached desperate circumstances was I forced to accept that I was a carer and that there were services out there that could make a difference, not only to me but to my family as well.

I was also a joint distance carer for my mother who had advanced Alzheimer's and that too was a time of huge anxiety and concerns as, like many, she did not recognise her difficulties and was not prepared to accept any support until we were forced to take action for her own safety.

Even though, at the time, I was someone who was a keen technology user, and we used some assistive technology to support my husband, it was very much a time when fewer opportunities were available and much more was to follow. Now we have a vast array of incredible choices

to change the way we communicate and allow carers to access the information, products, services and support they need.

There are many technologies which I would have given my right arm for, particularly in regard to keeping my mum safe. There were many times when she came to stay with me and would suddenly decide to take her dog for a walk just as I was in the midst of hoisting my husband to the bathroom. Which one should I help first!

Technology definitely should not be seen as just about the younger generation and we should not make any assumptions that older carers will not use technology.

Beyond my main caring roles for my husband, and my mum, for some years I have been supporting a couple of 98 and 100 years. Their daughter lives in Australia and, despite their age, the couple have continued to use both email and Skype to stay in touch with her.

Sadly, after 75 years of marriage, the husband died and now technology is even more important to allow the wife to learn to live alone and continue to be in touch with, and see, those who are so important to her, as well as ensuring that all her needs are met.

In supporting this couple, we decided to use Carers UK's app, Jointly. As the likely primary contact in the absence of their daughter, I am frequently the first person to be called in an emergency and I no longer have to worry about having the necessary information to hand as I can access it on Jointly wherever I am.

Previously, I solely had a hard copy of all their conditions and medications which I kept at home. It was always on my mind and did once happen that I went straight to the hospital from work and needed the notes to be able to help. Obviously, since then, I have felt

reassured that I could access those details anytime and that was my primary reason for wanting to use Jointly.

More recently, Jointly proved especially useful. Asked to take my friend to an appointment with a specialist about the use of a potential new drug, which cannot be easily withdrawn once started, I felt extremely responsible and noted during the conversation a passing comment about the drug's interaction with other drugs.

Although my friend was encouraged to start the drug with immediate effect, I felt ill at ease and asked for more time. On returning home, I did some research on the internet and discovered that the drug was not compatible with certain antibiotics. This was incredibly significant as my friend is allergic to penicillin and the use of antibiotics is essential.

It suddenly dawned on me that if I looked at our records on Jointly, I would be able to access the history of the antibiotics most frequently used to treat her and, to my shock, they were those that were incompatible with this drug. Without Jointly, I would never have made that discovery and was able to advise the daughter in Australia.

Jointly has given me the confidence to be able to give good support at any time, including at a time of crisis and has helped me to stay on top of things and allowed me to access information, including medication anytime, anywhere.

I think it is fair to say that technology has grown beyond anything we could ever have imagined, even five years ago, and sometimes we fear its use but, when it comes to carers, I personally have heard nothing but positives and hope that we will embrace it wholeheartedly."

Julie's story

Jointly has made managing medications easier for Julie and her seven siblings who share the care for their elderly parents.

Julie's mum is 86 years old and has dementia and arthritis while her dad is in his 90s and has diabetes, a heart condition and prostate disease.

Julie and her siblings all work and have families and have to juggle this alongside caring for their parents who live in North London. None of the children take a lead in their parents' care, as none live within popping distance, but they visit on a rota basis which means that each one ends up caring for an hour or two each week.

Sharing care with so many people means it's very important for Julie and her siblings to have easy access to information so that everyone knows what's going on – particularly with regard to medication. Julie has set up two circles of care in Jointly – one for their mum and one for their dad. Julie's mum doesn't have to take much medication while her dad takes a lot and Jointly has helped the family keep track of what medication her parents are on.

"For me the most important reason for using Jointly is keeping track of my parent's medication", says Julie. "It's very useful for everyone to know who's on what and have access to it. We go to hospital appointments with my parents and it's very useful to have that at hand, what the past history is and currently what's happening."

Caring has been difficult for Julie and her siblings and for Julie, Jointly has helped to make life a little easier. Julie states: *"For me personally it has relieved stress."*

She explains: *"Overall the impact of caring has been very stressful and frustrating. Seeing my mum relatively rapidly lose the will to live and being so poorly. She used to be a woman that never stood still. She used to be Chair of Governor's boards at schools, she used to be a teacher, a keen gardener - she used to do everything. She has now gone to doing nothing. You can't have a conversation with her anymore, she doesn't remember enough to have a proper conversation. She still recognises us but that will probably soon go too. Seeing her like that has been very difficult for me on top of trying to help from a distance and interacting with my seven brothers and sisters, their families and my dad."*

Julie says her dad previously didn't have a lot to do with running the house, leaving it all to her mum, but now he's the one in charge. *"He is the one who goes shopping and is the brains behind mum as well. Mentally he is on the ball but physically he is declining."*

"You think about it all the time and you can't think about it all the time as it takes over your whole life."

Jointly has also helped Julie in other ways. She likes the fact that key contacts are all in one place on the app and those of family members within the caring circles can be kept separately from others. Julie says: *"I have put the cleaning lady there. She is someone*

local who goes into my parents' home. We all knew she was Helen but no one knew what her surname was or her number. Now it's all on there."

As well as using Jointly the family call each other and swap texts to keep in touch. The siblings ask their dad to text them once a day to let them know he's all right. *"Dad has a very sweet system - he sends a text message with three dots to say he is ok. I don't know how we got to the three dots. Obviously if we don't get the dots we text each other 'have you got the dots?'"*

Rosemary's story

Rosemary, aged 62 from Essex, cares at a distance for both of her parents who live in Worcestershire. When her dad was diagnosed with Alzheimer's disease three years ago, her mum became his full-time carer and Rosemary his secondary carer. Both of her parents are currently in care – her dad, aged 85, on a permanent basis and her mum, aged 87, temporarily.

Rosemary is married and has two daughters in their twenties, making her one of the 2.4 million people in the UK who are sandwiched between providing care and support to an older relative and also their children.

Rosemary gave up work to care for her parents three years ago. Although it was originally intended to be a career break, it turned into early retirement as her parents' care needs gradually increased. Rosemary makes the three hour drive to visit her parents as often as she can; she does everything from providing personal care and online food shopping, to ordering medication and organising their finances.

"Caring for my parents has been emotionally and physically exhausting. It has also had an impact on our finances with me having to give up work. I really am lucky that my husband is so understanding and supportive."

When Rosemary's dad moved into a care home, her mum was left living on her own. This put Rosemary under added pressure to make sure her mum had all the support and care she needed. Rosemary saw an advert for Jointly in a magazine and thought it would be a great way to bring together all of the people involved in supporting her mum; that way, she could ensure her mum was being looked after and cared for in the best possible way.

"I am naturally an organised person, so having everything I need in one place is brilliant. I put a lot of time in to setting-up the app, but it was worth it. It's all there when I need it now – I can call mum's GP, get in touch with her neighbour, and even check if the gardener's been paid."

There are eight family members in Rosemary's mum's caring circle on Jointly – herself, her husband, three of her younger brothers, her two daughters and her niece. Rosemary can update everyone in the circle about changes in her mum's circumstances, without the stress and drain on her time of having to call or email everyone individually.

"When mum comes home, I'm going to ask some of the people from the community organisations that support her to join the circle. That way, when I'm not in Worcestershire, me and the family will know what mum's been doing, how she is feeling and how she is coping."

Rosemary thinks that Jointly is so useful that she wants to set up her own circle, so that she and her family can be prepared for anything that might happen to her in the future.

"I didn't know what to expect at first, but Jointly has been brilliant! I only wish I'd known about it sooner so I could have used it for my dad's care."