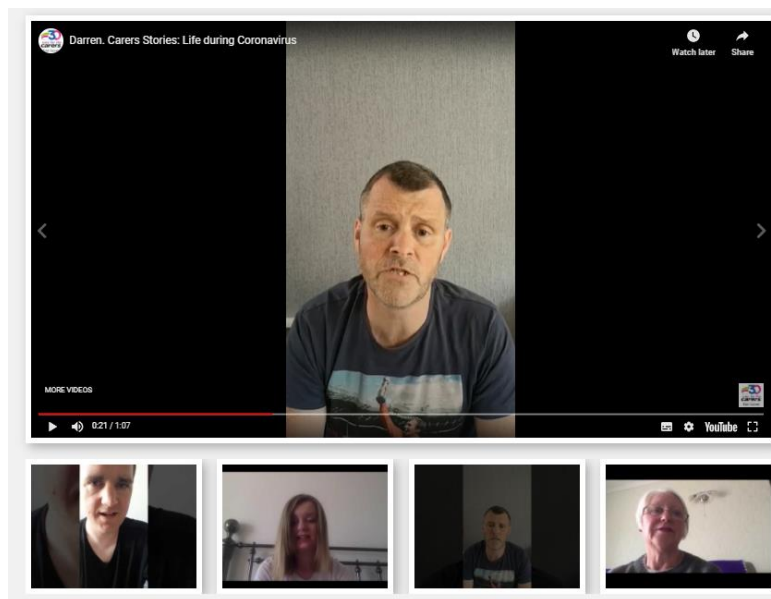


# Annual Carers Voices Conference

## July 2020



## Conference Report

*“At last I feel someone is listening, understanding and speaks the same language. I don’t feel quite so scared about the future now.”*





# Care for the Carers Annual Carers Voices Conference July 2020

## Healthy Caring, Healthy You

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### **Acknowledgements**

*Care for the Carers would like to thank all who contributed to making the conference a success – Fundraising Everywhere+ for supporting our online delivery, colleagues and partners that planned and delivered the workshops and speeches, partners that provided content for our online marketplace, and the carers themselves who shared so openly their experiences, opinions and ideas.*



With thanks to our funders:

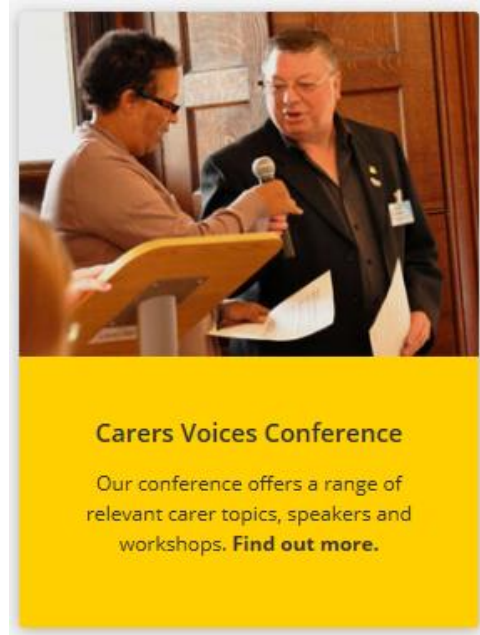


With thanks to our online delivery partners:



## Introduction – setting the scene

**Carers' voices often go unheard** – we frequently hear from carers that their views are ignored or undervalued, and that as a result, services and systems are designed without their needs in mind. With early feedback from carers during the Coronavirus pandemic that they felt more hidden than ever before, we realised it was essential to proceed with our Annual Carers Voices conference – albeit in a virtual format – in order to ensure that carers have a voice during these unprecedented times. The theme chosen for the July 2020 Annual Carers Voices Conference was **Healthy Caring, Healthy You**. This reflected feedback from carers that the pressures of caring often impact negatively on their health, alongside emerging concerns about increased pressure on carers during the pandemic.



The Annual Carers Voices Conference of 2020, like so many events this year, was **an engagement event unlike any that we had delivered before**. Originally planned as a face-to-face conference on a single day in July, the restrictions imposed by the COVID-19 pandemic resulted in a complete re-design of the conference format, to a month-long series of virtual engagement events.

The aims of the conference remained the same as our previous face-to-face Carers Voices events, despite having a different format, namely:

- **To keep carers informed and share information**
- **To bring carers together**
- **To listen to and amplify carers voices**

Building on the success of our previous Carers Voices events, we sought to incorporate the popular elements of keynote speeches, a live Q&A session with carer organisations, opportunities for carers to 'visit' the marketplace, and consultation workshops on the hot topics for carers – albeit delivered online. Crucially, we sought to retain the focus on listening to and amplifying carers' voices as the central aim of the conference, so a variety of opportunities for carers to have their say was an integral part of the conference planning.

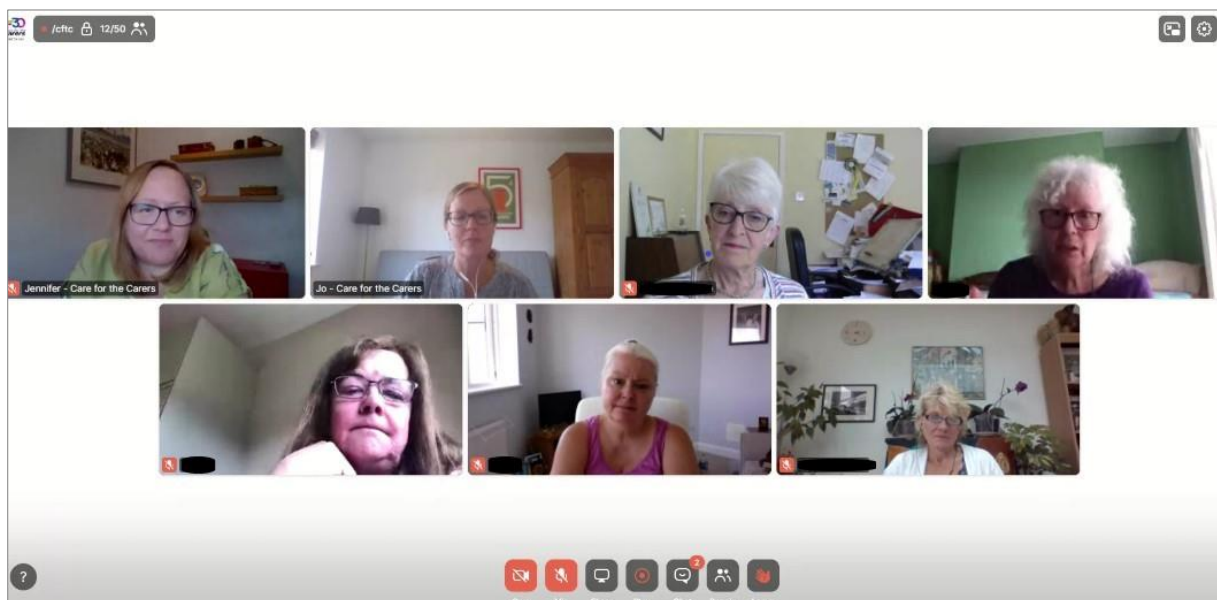
Aware of the barriers that an online conference would pose to some carers, we sought to both make the digital content as accessible as possible, and to provide non-digital methods for carers to engage with the conference content as well. This included taking the consultation workshop themes out for discussion with our carers groups taking place throughout the month, reaching those carers tentatively engaging with online carers groups but not available to attend the online conference workshops. We also obtained carers' views through one-to-one telephone discussions and invited carers to send written feedback.

## Attendance, engagement and evaluation

The majority of the live events were well attended, with 50 attendances across 6 live virtual events, by 27 carers and 9 professionals. The conference webpage achieved 523 unique page views, and the 23 Facebook posts about the conference had a reach of 7951 and 386 engagements. With the conference taking place online, some carers took part who would not normally attend our face-to-face Carers Voices events. However as expected, it did result in some carers not participating.

*“Carers in very challenging/unstable care situations often have no mental space or time to take part and so the very people who need to be heard most, are not. Likewise the problem of digital exclusion for those without either £ or knowhow to take part.”*

In an attempt to overcome these digital and time barriers, a further 61 carers were supported to contribute to the conference feedback through one-to-one and group discussion outside of the online conference events, meaning that **the feedback in this report reflects the views of 88 carers and 9 professionals.**



95% of carers completing event evaluations reported that they enjoyed taking part in the live sessions, and that they felt listened to and able to share their experiences, with the remaining 5% having encountered technical barriers to accessing the sessions. Narrative evaluation feedback about the live events was overwhelmingly positive, with many who participated commenting on the inclusive nature of the sessions.

*“I have joined in most of the sessions you have facilitated and have been very pleasantly surprised by getting the feeling of being listened to and sharing experiences - you don't feel so alone. Very good sessions. Well done to all.”*

*“There was so much respect in the 'room', I found it very emotional both telling our own story and hearing other people's, as we had so much in common.”*

## Key elements of the conference and methodology in capturing carers' feedback

### Online marketplace

With the marketplace usually a very popular part of our face-to-face carer engagement events, for the online conference we invited local carer services partners to provide video and/or written content for an



online marketplace, which was given a dedicated area on the conference website. Virtual marketplace stands were provided by 14 different partner organisations and projects for carers to visit and gather information. Services represented included Alzheimer's Society, Amaze, Association of Carers, British Red Cross, Care for the Carers, Coastal Wellbeing, Culture Shift, DISC Dementia Support, East Sussex Parent Carer Forum, East Sussex Young Carers, East Sussex 1Space, Healthwatch East Sussex, St Peter and St James Hospice, and Sussex Partnership NHS Trust.

The online marketplace received 51 unique page views, and the provider films achieved 100 views in total, varying between 4 and 19 views per provider.

### Keynote speeches and video content

With a live launch on 1<sup>st</sup> July 2020, a suite of video content was made available through dedicated conference pages on the Care for the Carers website throughout July, for carers to view at a time to suit them and fitting around the demands of their caring role.



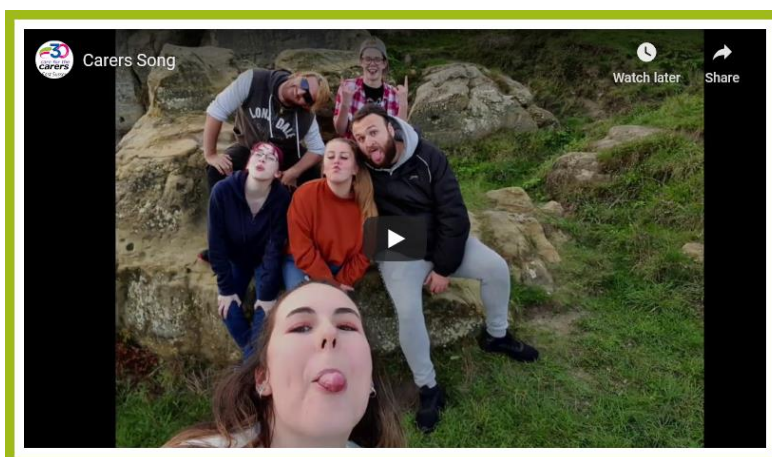
Jo Egan, Care for the Carers' Director of Services, introduced the conference, emphasised the focus of the day being about hearing and amplifying carers' voices, and explained the format of the events and ways that carers could share their views. The video was watched 72 times.

Care for the Carers' CEO, Jennifer Twist, shared the carer feedback we had heard so far regarding local carers' experiences during the COVID-19 pandemic and the actions Care for the Carers has taken as a result. She outlined the organisation's Carers Voices activities over the past year, based on local carers' views, and shared details of Care for the Carers' strategic plans for the next 5 years, based on carers' feedback, attaining 37 views.



Emily Holzhausen OBE, Director of Policy and Public Affairs, Carers UK, spoke about the national picture for carers during the pandemic, including outlining the findings from Carers UK's Caring Behind Closed Doors report<sup>1</sup> and their work to influence government responses to carers' needs through the pandemic, attaining 57 views.

Gareth Howells, CEO, Carers Trust, gave an update on Carers Trust's strategic focus for their work with carers and partners, and their commitment to making carers' voices the core of future plans, and was watched 46 times.



In keeping with our aim to make carers' voices central to the conference, carers' stories were profiled on our conference webpage, through films of carers speaking about the challenges faced through the pandemic and a music video of 'The Carers Song', which was written and performed by our Young Adult Carers group.

<sup>1</sup> Carers UK, Caring Behind Closed Doors -

[www.carersuk.org/images/News\\_and\\_campaigns/Behind\\_Closed\\_Doors\\_2020/Caring\\_behind\\_closed\\_doors\\_April20\\_pages\\_web\\_final.pdf](http://www.carersuk.org/images/News_and_campaigns/Behind_Closed_Doors_2020/Caring_behind_closed_doors_April20_pages_web_final.pdf)

## Live Q&A

A Live Q&A was facilitated virtually, and the recording made available to view on the conference webpage, with the panel comprising of the following:

- Emily Holzhausen OBE, Director of Policy and Public Affairs, Carers UK
- Tamsin Peart, Strategic Commissioning Manager, East Sussex Adult Social Care and Health
- Jennifer Twist, CEO, Care for the Carers
- Jo Egan, Director of Services, Care for the Carers



Questions and comments were invited before the live event and from the 14 carers and professionals who participated, with the themes arising detailed later in the report.

## Workshops

The following virtual carer workshops were organised, via digital platforms, with carers given the opportunity to take part by video or chat:

- ***A whole new world? – experiences of caring during Coronavirus***, facilitated by Care for the Carers
- ***Can you hear me? – exploring ways for parent carers to be heard above the noise***, for parent carers only, facilitated by Amaze and East Sussex Parent Carers Forum
- ***Is it just me? – an exploration of carers' experiences of, and solutions to, loneliness and isolation***, facilitated by Care for the Carers
- ***Managing the maze – making Health & Social Care Systems work for carers***, facilitated by Care for the Carers
- ***Digitally included? – what carers need online***, facilitated by Care for the Carers
- ***Don't forget me – young carers' health & wellbeing***, for young carers only, facilitated by East Sussex Young Carers

Unfortunately, the young carers workshop was cancelled due to having no one booked to attend, but the others were attended by between 6 and 10 carers each.

Aside from a small number of carers commenting on some technical difficulties, the strongest feedback coming through in the workshop evaluations was the positive benefit for carers of coming together and sharing experiences, chiming with the feedback we hear at every Carers Voices event we run.

*“It was really humbling to listen to other people's experiences, and hear the different views, difficulties and positives.”*

*“Really enjoyed taking part and hearing others in same position as me.”*

## What carers said – key themes

During the live Q&A, workshops, group and one-to-one discussions, and through evaluation surveys, carers shared their personal experiences of the day-to-day reality of being an unpaid carer in East Sussex, including reflecting upon the impact of the COVID-19 pandemic.



The following themes arose:

- 1. Experiences of caring during Coronavirus were mixed, with many carers experiencing increased pressures and significant crisis, and some carers reporting some positive benefits.**

Increased isolation and stress as a result of the lockdown restrictions was a strong theme, with particular challenges faced by those carers who were previously supported by day centres, respite provision, and specialist provision for children and young people with SEND, and those who are caring for people who do not have capacity to understand the reason for the restrictions. The majority of the carers we spoke to reported that their caring roles significantly increased during Coronavirus.

*“The day centres and respite just vanished for my husband. It felt like I was just abandoned. There were no alternatives. I never realised just how much I relied on those places.”*

*“I’ve got really down at times. My wife doesn’t understand the restrictions. It makes it much more difficult.”*

*“I have felt isolated and lonely. It’s really hard not having anything to look forward to.”*

*“Night times are one of the hardest times. I try to get a good night’s sleep, but my mind goes over and over things. I can’t switch off.”*

Many carers reported the negative impact on their wellbeing caused by confusing messaging about shielding and lockdown restrictions in relation to caring responsibilities, along with practical challenges in obtaining food and prescriptions, particularly during the early days of the pandemic. The extra time needed for dealing with these challenges, such as queuing for long periods at a supermarket, or having to travel to several shops or pharmacies to obtain essential supplies, impacted on carers’ tiredness and ability or time to work or do other activities.



*“I had to stay up until midnight to try to get a shopping slot. Less sleep was the last thing I needed during that really stressful time.”*

*“It is difficult to know what we can do and what is safe.”*

Those who were new to caring and without established support reported feeling particularly vulnerable during the pandemic, and all the carers we spoke to described having to “muddle through” and find out what support was available, with various changes to services but often poorly updated information.

*“I spent what seemed like hours on the phone trying to get answers, only to be told there is a global pandemic. Something that I did already know.”*

Access to Personal Protective Equipment (PPE) was a major issue for some carers, and again an area where there was significant confusion.

*“I struggled to get hold of the PPE our Personal Assistants needed, and when I did, it was 3 or 4 times more expensive.”*

Several carers reported that as a result of the lockdown restrictions, the condition of the person they care for significantly deteriorated.

*“I used to be able to take Mum out and about, as we could manage the transfer into the car, but she’s lost muscle strength during lockdown so we won’t be able to do this now. I worry about what that means for the future as it will be a lot harder to get out.”*

Some carers reported that they feel better since the restrictions have been eased slightly and they can at least get out a bit more, but there are still concerns about the virus and its impact, and for some carers, they feel that they are being left behind whilst the rest of the world moves back to normal.

*“My anxiety and stress levels have gone through the roof at times. I have to shield and it seems that some people just flout the regulations. They could be passing it on to anyone. I’m doing my bit but because of others I’m scared to death that one of us will catch it.”*

Uncertainty about making the right decisions was also highlighted as a concern for carers, both during the pandemic and beyond.

*“The loss of control over my own life is hard. The level of uncertainty is difficult and makes trying to make ‘sensible’ decisions harder.”*

*“I’m worrying constantly about the situation as to how long my mum will be able to remain at home with live-in care workers and when will she need to move in to residential care. What really is the situation with care homes and what does it mean for her? I don’t know what the ‘wise’ decision is.”*

Carers frequently cited the positive benefits of accessing support during these challenging times, with particular value placed on flexible interventions which responded to carers’ individual needs.

*“The day centre my husband was going to closed, but someone suggested that I ask for a sitting call instead. I asked Adult Social Care about it and they arranged it within a week.”*

*“My son is an inpatient on a mental health ward, and the team there have been really good at keeping in touch with Skype calls.”*

*“The weekly calls from the Dementia Support Service were helpful.”*

*“Care for the Carers were very helpful when I was struggling with my husband’s anxiety. Having that number to ring and someone to talk to, to reach out and to talk with other carers going through similar issues [at an online carers group] was brilliant.”*

*“I’m fed up with cooking and housework, but then I remembered we are part of Forest Row Gages group. They helped and we had a lovely meal. Little gifts from the community that they organized were very uplifting. It’s nice to know lots of people in the area care.”*

*“The NHS Mental Health Team have been really responsive regarding my partners’ mental health needs.”*

*“Having the online Carers Groups and using Zoom to communicate with friends and family has helped.”*

For some carers, the generally poor level of carer awareness within the community, which carers regularly report, was worse during the pandemic.

*“Everyone is focused on the NHS – not carers – and we work longer hours!”*

*“I’m judged by strangers when I’m shopping for myself and others because I have double amounts in my trolley.”*

Some positive impacts of the pandemic were identified, along with concern that these may be short-lived, with some carers noting that the absence of appointments and visitors meant that they had less pressure on their time.

*“It seems almost ironic but since the lockdown it has meant that there is more continuity in my son’s care. The same paid carers attend every time and my son’s mood has never been better. I just worry that we might lose that when things get back to normal.”*

*“I’ve appreciated the regular calls from Adult Social Care – I’ve had way more contact from them than in normal times, so it’s a shame it probably won’t continue.”*

*“It was really easier at first, as we had nowhere to be and nothing to do, so I didn’t have to worry about how he looked or what time he needed to be where. Now this has gone on for so long, I really need a break though.”*

*“I’ve had more time with my family and I’m saving money.”*

*“My husband has been working from home so I’ve been able to go out for a walk, which I wouldn’t normally be able to do.”*

Carers shared information on a range of coping strategies which they had found useful during the pandemic, such as gardening, dog-walking, drawing, online courses, gaming, meditation, connecting with friends online, setting routines, walking and running, with several noting that they aim to continue these as permanent habits.

Physical activity helps me, especially if I have to focus on what I'm doing (so as not to fall over etc). It helps control my tendency to overthink things

*“Taking part in Zoom webinars to help me better understand my mum’s condition I’ve learnt a lot and the interaction was great. Meeting up with old school friends online has been supportive and I wouldn’t have done previously.”*

However, the feedback magnified the gulf between those carers who have resources such as gardens, larger homes, disposable incomes, and support with their caring role, and those living in cramped conditions in the deprived areas of the county and struggling financially. The former often described the positive elements of the lockdown restrictions, whilst the latter had experienced significant challenges and crises.

## **2. Carers experience loneliness and isolation as a result of caring, which can be overwhelming and debilitating**

Carers told us that loneliness and isolation is a common impact of being a carer and that once they became a carer life is different. They described the isolation which comes about from poor levels of carer awareness amongst the general population. Carers told us that people often have no understanding of what their days look like, or they stigmatise carers and the people they care for.

*“My children have learning disabilities, so there’s a feeling of exclusion when other parents talk about the things their children can do. Some parents don’t want their children to mix with mine, so you get left out.”*

*“Family and friends don’t get it – they expect me to get in touch, but my day is full, and they don’t realise what my day is like. That makes me feel worse.”*

*“I won’t talk about things happening at home with friends. I’m at the start of my carer journey and I get no interaction from people.”*

*“I’m home schooling two autistic children, which is very isolating and affects mental health. There’s often no time for self-care. My life is one role as a parent carer.”*

Isolation in decision-making was identified as a key challenge for carers, compounded by inconsistent information about carer support, with many carers feeling that they are on their own and not knowing where to turn.

*“I feel loneliness most when having to make decisions. I ask, ‘What’s in her best interests?’ and sometimes feel overwhelmed by small things.”*

*“Being alone with the task of caring is challenging.”*

*“You begin to settle then when something new and important point in their lives happens, loneliness increases – How do I cope with this one? Who can help me? Where do I go? What happens now? What will happen then? It’s lonely not knowing where to turn.”*

The complexity of the psychological impact of caring was also identified as a cause of isolation, with carers reporting the guilt experienced when they feel negative emotions about caring, and the bravery needed to acknowledge and discuss this.

*“The loneliest thing is feeling resentful of being a carer. And I don’t want to define myself as a carer in every conversation, so there’s a struggle internally.”*

*“Caring is boring and I don’t have my own space. You feel guilty about thinking about plans of what you’re going to do when the person you care for dies, but I chose to be in this caring role and wouldn’t have it any other way.”*

*“Loneliness is very hard to admit to – you first have to be brave to admit to yourself, then you can get help. Connecting with the Carers Centre has abated my loneliness – there’s a sense of community with people who understand.”*

Carers highlighted that caring prevents them from undertaking certain activities, resulting in isolation. They described a range of opportunities they have lost: work, friends, travel, future plans, and shared activities with the people they care for.

*“I’ve lost friends because they don’t get it when you say you can’t go out.”*

*“My time caring meant I wasn’t spending time with my family.”*

*“I grieve for the career that I would have had after my kids left school, had life been different and I hadn’t been caring.”*

*“The unpredictability of their condition means plans might fall through, so I just think, ‘best not to make plans in the first place’. I’m putting life on hold for the ‘just in case’. I have to hold back to keep some energy for the next crisis.”*

Carers described a range of coping strategies they use to overcome loneliness and isolation, including connecting with other carers, exercise, learning, making time to speak to friends, and planning something to look forward to.

*“Not having any social interaction increases the feeling of loneliness, our Zoom meetings have been something to look forward to.”*

*“I have a Facebook page for parent carers and we organise meeting up. It helps to connect with people who ‘get it’.”*

*“Meeting other parent carers and sharing experiences can be very positive.”*

*“Support from the DISC service has been brilliant.”*

*“It has been difficult at times but it makes me feel so much better to know that people like [Care for the Carers] are here for me whenever I need you.”*

### **3. Carers do not receive relevant information and support when they need it, and Health & Social Care systems do not consistently work effectively for carers**

Access to timely information and support for carers was frequently cited as an unmet need. Opportunities to identify carers early and refer them for support were missed by Health and Social Care agencies and community organisations, information provided by services did not take carers' needs into account, and carers described having found out about carer support services seemingly by chance rather than as a routine response.

*“There is loads of support out there, but you have to hunt for it. Everybody has to learn from scratch, it's like you're the only person who's been through it.”*

*“It's tiring when seeking help to have to 'go round the mulberry bush'.”*

*“A year or so ago we went for an Occupational Therapy assessment, which resulted in a couple of things provided to help us in the home. It was surprisingly good, but didn't seem well signposted. It's hard to remember how I got this set up. I worry that if they don't speak to the right person, other carers might miss out.”*

*“For the first 6 weeks after my dad's diagnosis, I had lots of communications from several different departments who had similar questionnaires and you never knew who you were talking to – it led to complete confusion. Then I had no contact for two years until I went looking for help. I received apologies about being left alone, and again had lots of information thrown at us from everyone, names, numbers and so on.”*

*“My GP didn't know anything about what equipment is available, and was even keen to learn from me as they thought it would suit their own mother!”*

*“What would make things easier would be if the people we care for were actually given proper diagnoses, and actual health and social care to meet their needs. Then we wouldn't be having so much trouble as carers.”*

*“When a child has been given a diagnosis there needs to be a better system for providing immediate information about the support and services available.”*

Carers reported a number of barriers to accessing services. They had concerns that people don't know what help they are eligible for and think there might be a cost attached to help and/or equipment, which puts them off reaching out. Poor communication between services was frequently experienced, with carers having to repeat their story. Parent carers reported that having to access certain levels of support, for example via Children's Social Care Level 4, has a stigma attached.

*“The lack of joined up thinking is the most frustrating thing.”*

*“Systems are separate, NHS and social care not talking to each other.”*

*“Not knowing how anything worked, the way through the maze, has caused me so much stress it made my hair fall out. There's no joined-up thinking, I'm battling for everything, being passed back and forth. It's all terribly dysfunctional. I have to pursue everything. Person-centred care is a notion that I've not seen any evidence of.”*

*Everything is fragmented as far as care is concerned. People are seen as a collection of separate body parts to treat.”*

*“Respite for children with special educational needs and disabilities needs to be regular enough that the staff can learn how to support the child/young person’s individual needs, which are often complex.”*

*“I think a lot of people are reluctant to ask for help because they worry they won’t be able to afford the things they need.”*

*“Trying to find domiciliary services for my mum has been hard, in particular dental services, who will not do home visits unless it is an emergency, even though it is known that dental care is crucial in the elderly. The system works against itself.”*

*“It’s most frustrating having to tell my story again and again and again. There’s no sharing of information. Explaining what’s happened and what the situation is to every person you speak to is draining.”*

Inconsistency in response to carers’ needs by Health and Social Care was a strong theme. Some carers reported positive experiences of supportive listening coming from health professionals – including a GP and a Paediatric Consultant’s response to two parent carers – and one carer noting that registering as a carer with her GP had positive results. Access to services has been difficult for most carers, however, with carers reporting their experience of a continued struggle to get the help needed, and this struggle having been compounded by the pandemic.

*“There is a constant need for carer awareness. I’ve had district nurses arrive with no appointment to see my mum without me there, when she is not able to describe what she needs. Services need to communicate with carers – consistently.”*

*“The experience of being a carer of someone who uses mental health services has been a mixed bag. It has been a lonely journey. I’ve encountered a few good champions, but I’ve had to fight for his care every step of the way. I was told by services that you need to fight for things even once you’re in the system – and it’s a complicated system.”*

*“There is too much inconsistency. Services need to communicate quicker, better, and clearer.”*

*“[During COVID-19], you can’t get through on the phone to the hospital and you’re not able to get any non-urgent treatment from them if you do get through. You can’t get a GP appointment for routine injections or anything, so what’s the point? My mum can’t get her regular B12 injection or her 3 monthly pain-killing injection, so she is really suffering at the moment and I don’t know what to do.”*

*“Mental health support services are less available and supportive [during COVID-19] – if you can’t do video or phone calls, Health in Mind close your case.”*

Carers emphasised the importance of Health and Social Care practitioners taking their views into account, and involving them in care-planning and decision-making. They described the failure by some services to recognise the expertise which carers can

bring, and this having a negative impact on both the carer's wellbeing and the care plan for the person they care for.

*“Parent carers often feel professionals don't understand, or even trust, their views. This can leave families feeling isolated and that their situation is unique.”*

*“Carers can help health and social care staff, as they know person they care for, but services don't seem to want to benefit from that information.”*

Carers spoke positively of the variety of support they have accessed since finding out about that is available, and gave examples of when services give appropriate and timely support.

*“Age UK were phenomenal – they got me started and did a benefits check. I've really appreciated the voluntary sector. Care for the Carers' forums have been very useful for information and support. DISC were also great. Alzheimer's Society CrISP programmes have also helped a lot. Social services have provided equipment at no charge.”*

*“Thank you Care for the Carers for helping me find my voice through writing and photography.”*

*“When my son was admitted to an acute mental health ward, there was a carers pack on arrival, with loads of information, on paper, that I could go through in my own time. It was really useful.”*

#### **4. Carers have a range of digital needs, including digital training, targeted, concise and accessible digital information, as well as the option to access services non-digitally**

Several carers described the positive impact which the lockdown restrictions have had in pushing them to use digital technology that they might otherwise not have used, particularly older carers. Carers also valued the positive opportunities there have been to use technology to connect with others during these isolating times. A quick poll in one of the conference discussions saw 67% of carers stating that they were only using digital platforms as a result of the pandemic, compared with 33% stating they normally use digital platforms.

*“If the lockdown hadn't happened we wouldn't have to know any of this, especially in my age group. I was hoping I wouldn't have to learn any more software for the rest of my life, but now I realise that's not going to be the case.”*

*“I am using a lot more social media now, to keep in contact with people, and overall I'm finding it is positive.”*

*“I do find that checking in once a month [at my online carers group] about what's going on is really valuable. It's been really great.”*

*“It's great being able to use Facebook Messenger as it can be difficult speaking on the phone in front of the person I care for.”*

*“I’ve found it helpful that I can view webinar recordings and dip into online training at a time that suits me.”*

*“There have been loads of free accessible courses during lockdown – I hope that continues. I’ve been part of a course where the facilitator is available for an hour and you can ask questions.”*

*“I’ve really enjoyed using Facebook Rooms for our Young Adult Carer group and for getting together with friends.”*

A significant number of barriers to digital engagement were cited, including various levels of technical knowledge, learning difficulties impacting on accessibility, equipment or software being out-of-date and costly to keep updated, a preference for face-to-face contact, and limited privacy to enable digital engagement.

*“It can be a bit overwhelming and daunting – we need training.”*

*“It’s really hard to level the playing field, because we’re all at different levels.”*

*“My software is getting older and older. If it’s no longer being supported, eventually I won’t even be able to get on to things through it, so it’s this question of being forced to upgrade. I’m a bit concerned about that going forward as it’s expensive stuff. Things become obsolete after a while, so it’s a concern I have about how to stay connected in the long term”.*

*“I don’t have a mobile that’s smart!”*

*“Privacy is an issue with other people in the house.”*

*“I have an open plan living space, so for personal meetings I have to use my bedroom which is not always ideal.”*

Digital fatigue, carers not having enough time to spend online or sift through the high volume of information available, and carers feeling overwhelmed or pressured by digital options were strong themes coming through.

*“Quite often I can’t catch up with everything and everyone, and its extra pressure.”*

*“Tech fatigue set in so I’ve moved to reading a physical newspaper.”*

*“I get sick of computers!”*

There were suggestions for organisations to undertake more targeted digital messaging and marketing, in order to help carers to focus on information of specific interest or relevance, and to offer more live information sessions digitally.

*“There’s an opportunity for Care for the Carers to do more active targeting about what’s on. I pick out bits from the newsletters but I go looking for it – others may not see it. It helps when I get specific texts or invites to workshops.”*

*“Younger people like interactive content like polls and quizzes, or content shared with local community pages, so that’s where organisations need to share what’s going on.”*



*“A digital buddy system would be great as a new carer. It’s valuable getting answers and someone to connect to.”*

Several carers we spoke to identified the need for support to increase their digital knowledge and skills, but were unaware of the support available to carers through the Computer Help at Home service<sup>2</sup>, facilitated by the Association of Carers [Nb. information about the service was subsequently shared with these carers].

*“I want to get myself a smartphone and I haven’t got a clue what I need or where to start. I’d love to have a person who could walk me through and tell me what I need to do.”*

*“Basic training would be helpful.”*

*“Physical teaching is needed for some people as they get overwhelmed.”*

*“Making training fun and relevant inspires people, and builds their motivation to achieve.”*

Some carers noted the ways that digital options can support them in their caring role, whilst others noted their preference for accessing support offline.

*“I was able to quickly set up priority shopping deliveries due to being good with technology.”*

*“Zoom and all this virtual staff is not the same as meeting up face-to-face.”*

*“A lot of stuff I’m not doing because I don’t want to. I don’t want to be on Facebook.”*

*“Somehow it makes it easy to talk safely from home and behind a screen - BUT I still don’t like too much technology!”*

Mirroring much of what was raised by carers at the live workshops, the following further themes and issues were raised and discussed at the Live Q&A event:

5. Feedback that **the level of Carers Allowance represents “an insult to carers”** – being the lowest welfare benefit and not available to many groups of carers.
6. Feedback that **carers should have a legal right to time off work** to support their caring responsibilities. A government consultation on Carer’s Leave was underway and the time of the conference, and Care for the Carers submitted a response reflecting carers’ concerns about this issue.
7. Feedback about **the need for a flexible and carer-aware response from Health and Social Care** – with an example given that health appointment letters do not routinely reference the option for carers to access the grant available through Care for the Carers for replacement care whilst they attend health appointments, and this resulting in carers not having their own health needs met.

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<sup>2</sup> Association of Carers’ Computer Help At Home is a service where a volunteer teaches carers how to use the their computer in their own home – see [www.associationofcarers.org.uk/what-we-do/computer-help-at-home](http://www.associationofcarers.org.uk/what-we-do/computer-help-at-home)

8. Concern about how COVID-19 is affecting Black Asian and Minority Ethnic (BAME) communities and feedback that **organisations must actively make sure that carers from BAME communities are supported.**
9. Concern that the 'clap for carers' during the pandemic, which was aimed at paid care staff, represents how the country ignores and undervalues unpaid carers, and highlights how **greater carer awareness is much needed.**
10. Concern that **carers of disabled children and young people are in crisis, exacerbated by the pandemic**, exhausted after three months without their children going to school or college, and often without some or all the short breaks or support from Personal Assistants that they may usually have.
11. Concern about what impact COVID-19 and the resultant economic crisis will have on **home care and care home provision** in East Sussex. Carers were advised that East Sussex County Council (ESCC) are in the process of planning the recommissioning of home care services in East Sussex and have been engaging with local providers to understand the impact that COVID-19 has had on their organisation, workforce, clients and their care workers.
12. Feedback that **the decision made to remove any personal identification from the Carers Card was unhelpful**, and confirmation that a signature strip has now been added to new Carers Cards being issued.
13. Concerns about **access to Personal Protective Equipment (PPE) in the early stages of the pandemic**, in particular for carers employing Personal Assistants (PAs) through Personal Health Budgets or Direct Payments. ESCC advised that PPE supply arrangements are now in place, with the Council supporting PAs directly with access to PPE following the government's Infection Control Fund to local authorities. ESCC noted that carers can expect to see the continuation of support being provided with increased infection prevention and control procedures in place.

## Recommendations

The carer feedback gathered through the Annual Carers Voices Conference 2020 informs the following recommendations:

1. **Statutory and voluntary sector COVID-19 response planning should take carers' needs into account, including: recognition, clear information and communication, flexibility, and timely support.**
2. **Organisations should consider the disproportionate impact of COVID-19 on BAME communities and the associated increased prevalence in carers from BAME communities, and work collaboratively to reach these carers.**
3. **Carers should be given regular access to timely, relevant information and support, enabled through the following measures:**
  - a. **Health and Social Care and voluntary sector practitioners should undertake Carer Awareness training as part of induction;**
  - b. **Carers should be routinely identified by Health and Social Care and voluntary sector practitioners and offered referral to the Carers**

- Centre, at an early stage and recurrently throughout their caring journey;
- c. Health appointment letters should include standard text regarding carer identification and support;
  - d. Health and Social Care and voluntary sector organisations should implement effective referral pathways to reduce the need for carers to repeat their story to multiple services.
4. Services should be delivered through both online and offline formats, in order to meet the range of carers' digital engagement levels, using digital methods to include those carers unable to access face-to-face services and using offline methods to include those carers who are digitally excluded.
  5. Carers' digital inclusion support should continue to be made available and promoted more widely, in order to increase carers' capacity to engage with the digital information and support available.
  6. Carers should be given opportunities to talk about the impact of their caring role, including through emotional support, counselling, and peer support, and should have timely access to support, advice and guidance.
  7. Care for the Carers should continue to work in partnership with national carers' organisations, and support Carers UK's 'Fairer for Carers' campaign, to lobby for an increase in Carers Allowance levels and an overhaul of carers' benefits that recognise the enormous contribution carers make.
  8. Employers should implement a range of carer-friendly employment benefits, including Carer's Leave, flexible working, and referral for support.
  9. East Sussex County Council should consult with carers when planning the recommissioning of home care services in East Sussex.

## Next steps

The key findings and recommendations from the Annual Carers Voices Conference 2020 will be presented at a range of strategic meetings, shared with key decision-makers, partners and all who participated in the conference, and used to inform Care for the Carers' strategic and operational planning. Care for the Carers will seek to influence partners to commit to action which will achieve positive change for carers in relation to the recommendations, and progress updates will be shared via our various communications channels.

*This report uses feedback from the carers and professionals participating in the conference. For further information please contact Jo Egan, Director of Services, by email: [joe@cftc.org.uk](mailto:joe@cftc.org.uk) or by telephone: 01323 738390 ext. 218.*

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