



“It was good to hear what others had to say. As it was my first forum, very enlightening – I felt good giving my viewpoint and sharing with others.”

“You told us that agencies in East Sussex don’t communicate well with one another. It’s clear that there needs to be a change and it’s time to do something different.”

CARERS VOICES FORUM AUGUST 2019

**Achieving a
Carer-Friendly East Sussex**

Care for the Carers Carers Voices Forum August 2019

Achieving a Carer-Friendly East Sussex

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Executive summary

Introduction

The Carers Voices Forum, held on 30th August 2019 at Uckfield Civic Centre focused on the theme, ***Achieving a Carer-Friendly East Sussex***. Attended by 40 carers and 2 people they care for, along with Care for the Carers staff and 39 other professionals and partners, the aims of the day were as follows:

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

The engagement event hosted keynote speakers from Care for the Carers, Carers UK, Adult Social Care and the NHS, market place stands providing information and support to carers from a range of local services, and workshops consulting with carers about action needed to achieve a carer-friendly East Sussex.

Recommendations

The discussions held at the August 2019 Carers Voices Forum built upon the priorities identified at the February 2019 Carers Voices Forum, in order to equip partners with a better understanding of what local carers say is necessary to achieve a carer-friendly East Sussex. **Carers strongly endorsed the need for a cross-sector plan or strategy in East Sussex to bring about necessary change.**

Statutory and voluntary sector partners should therefore consider the feedback detailed in this report when developing a shared plan to address the following carer priorities:

- 1. Carers should be routinely identified by Health and Social Care practitioners and community organisations and offered referral to information or support.**
- 2. Services and systems should work better together to meet the needs of carers in East Sussex.**
- 3. National government needs to make changes to employment law and welfare benefit systems to better meet carers' needs and reduce the negative financial impact of caring.**
- 4. Carers need to be given a range of opportunities to take time off from their caring role.**
- 5. A range of carer services should continue to be made available in East Sussex.**

Next steps

The key findings and recommendations from the August 2019 Carers Voices Forum will be presented at a range of strategic meetings, shared with key decision-makers, partners and all who attended the Forum, 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 and at Care for the Carers' Annual Carers Voices Conference.

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. The theme chosen for the August 2019 Carers Voices Forum was ***Achieving a Carer-Friendly East Sussex***, in response to feedback from carers at previous Carers Forums and through our Carers Voices Network.



Now an established and popular event for East Sussex carers and the organisations who seek to support them, the format of the day built on feedback from previous Carers Forums, consisting of keynote speeches, opportunities for carers to visit the marketplace, and consultation workshops. The aims of the day were as follows:

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

Listening to and amplifying carers' voices is the central aim of our carer engagement work, so time for carers to have their say was an integral part of the day, both in the questions session following the keynote speakers, and the afternoon workshops.

The event was held at Uckfield Civic Centre. This choice of location in the High Wealden, Lewes and Havens Clinical Commissioning Group (CCG) area was in keeping with the efforts at previous Forums to give carers from across the county an opportunity to participate in our engagement work by alternating the locations of the Forums between the three CCG areas in the county.



This report uses feedback from carers, partners and guests, notes from workshops and carers groups which captured carers' views, experiences, concerns and ideas and any additional feedback received after the event. For further information please contact Jo Egan, Director of Services, by email: joe@cftc.org.uk or by telephone: 01323 738390.

Attendance and overall evaluation of the day

The event was well attended by a mix of people, including 40 carers and 2 people they care for. 97% of carers completing the evaluation question giving an overall rating of the Forum assessed the day as good or excellent.



Key elements of the day and methodology in capturing carers' feedback

Marketplace stands, networking and socialising



This is a very popular part of the day for both carers and partners who seek to engage with them. **Marketplace stands were facilitated by 18 different partner organisations and projects** for carers to visit, share experiences and gather information. Services represented on the day included:

Age UK East Sussex, Association of Carers, Care for the Carers, Connecting4you & High Weald, Lewes & Havens CCG, Cranstoun – East Sussex Family & Carers Team, East Sussex County Council (ESCC) – Safeguarding Development Team, ESCC – Support with Confidence, Healthwatch, Heringtons Solicitors, ICE Project, Macmillan East Sussex Welfare Benefits Advice, MS Society group for Uckfield, Lewes & Heathfield, Remploy, Southdown, Sussex Partnership NHS Trust, Sussex Support Service, Time for Dementia and Wealden Citizens Advice.





The best thing about the day was...

“...meeting organisations, people, advice and signposting.”

“...hearing about the [Carers] Hub, meeting carers and [the] stands...gaining more knowledge and information. Being in a sympathetic, caring environment.”

“...feeling of fellowship, shared goals. Hopefully Care for the Carers can be a true HUB to give varied, centralised information.”

Carers frequently cited the positive impact of feeling connected to and socialising with other carers as a result of attending the Forum, and the value of coming together was also referenced in the opening speeches. Jennifer Twist, Care for the Carers’ Chief Executive noted, *“The Forums are here to strengthen the evidence base about what, as carers, you need and want, so that local services and organisations develop with a better understanding of what it means to be a carer – and together our voices are louder.”*



The best thing about the day was...

“... meeting so many carers and listening to their experiences.”

“...being able to come away from [my] caring role for a few hours, with other carers with similar problems.”

“...meeting other articulate carers.”

Keynote speakers

Care for the Carers' CEO, Jennifer Twist, introduced the day, emphasised the focus of the day being about hearing and amplifying carers' voices, shared information about the organisation's funding position, its 30th Anniversary celebrations, and the need to work collaboratively to develop and East Sussex Carers Strategy.



Jo Egan, Care for the Carers' Director of Services, outlined the detail of the new Carers Centre model, which Care for the Carers will be delivering from October 2019.

Caring 2019 report, and



Tamsin Peart, Strategic Commissioning Manager, Adult Social Care and Health, East Sussex County Council and NHS, informed carers about the recent commissioning for carers services, and shared details regarding which services have been commissioned.



Keynote speaker, Emily Holzhausen OBE, Director of Policy and Public Affairs, Carers UK, spoke about the national picture for carers, including government response to carers' issues, findings from the State of

Feedback regarding the keynote speeches was positive, with 100% of carers completing evaluations rating them as good or excellent.

“Loved having a national presence speaker.”

“Great questions (always need more time for feedback). Carers took part really well. Great points addressed.”

Questions and comments were invited from carers and professionals following the speaker sessions, and the following themes emerged:

- Clarification questions about the Carers Centre delivery model and other support available to carers, with positive comments made about the support available – including a powerful story shared by one carers about how much has improved since she became a carer in 1971
- Positive feedback about a proposal to adapt the East Sussex Carers Card to become a 'carer passport', using lanyards, assisting with identifying carers in settings such as hospitals

- Examples of both excellent carer-friendly practice, including Wealden Dementia Action Alliance and Eastbourne eye hospital, and poor responses to carers by mental health services (individual support was subsequently offered)

Workshops



Carer workshops were facilitated by Care for the Carers' staff, with the aim of gathering carers' views on specific actions needed to achieve a carer-friendly East Sussex, drilling down into *how to achieve*

the five priorities identified at the February 2019 Carers Forum, as follows:

1. **Routine carer identification**
2. **Effective services and systems**
3. **Reducing the negative financial impact of caring**
4. **Breaks from caring**
5. **Carer support and engagement**

Overall the workshops received very positive feedback from carers completing evaluations, with 100% of respondents stating that they felt listened to and able to share their views and experiences.

“Workshop was good. Interesting to hear others insights. I felt I was listened to and heard.”

“Providing potentially isolated people with a voice and like-minded friends. Amazing.”

“The best workshop I’ve ever been to – it makes such a difference to feel listened to. The workshop structure gave us space to have our say and be heard.”

Rather than running a separate workshop for the professionals attending this Forum, we invited partners to attend the carer workshops, and this change was well-received. Several professionals cited, *“hearing from carers & their experiences”*, as the best thing about the day.

What carers said – key themes



During the workshops, through evaluation forms, and in conversation throughout the day, carers shared their personal experiences of the day-to-day reality of being an unpaid carer in East Sussex. They confirmed that the priorities identified at the previous Carers Voices Forum in February 2019 (detailed above), are still their

key priorities, and that they support the need for a cross-sector Carers Strategy to bring about necessary change. The following feedback was given in relation to each priority:

1. Routine carer identification

Carers identified GP surgeries and hospitals as key agencies that are often missing opportunities to identify carers and offer them support.

“There is a gap in carer identification at GP surgeries. The GP doesn’t always communicate about carer support, or is aware of Care for the Carers, and no one is there to advise us.”

“Carers should be recorded and a record kept at GP surgeries and hospitals.”

“There should be routine checking with patients of who their carer is.”

“GPs need to make it easier to recognise me as a carer.”

It was noted that whilst a GP Carers Register is useful, GP surgeries having a carer register needs to be one part of their carer-friendly practice, such as using it as a passport to accessing flexible appointments and free flu-jabs, not their only offer for carers.

“The fact you’re on their Carers Register doesn’t make any damned difference!”



Carers identified that there is a role for all frontline staff within health and social care settings, banks, police, care agency staff, pharmacies, and employers, to develop carer-friendly practice, highlight this by sharing examples of good and poor practice. Several carers raised the importance of mandatory Carer Awareness Training, including for council staff, GPs, and GP receptionists, who were described as *“often the first people that carers speak to”*.

“Some receptionists in GP practices are less than helpful – they’re robots”

“Lighthouse surgery were good and have a nurse to support carers.”

“Employers should know to identify carers.”

The potential for carers themselves to support the work to identify carers was flagged up. Patient Participation Groups (PPGs) were noted as a key opportunity to influence carer-friendly practice within GP surgeries, with several carers noting that they participate in their PPG as Carer Representatives, and we agreed to run a focus group with these Representatives later in the year.

“PPGs are dying to be helpful!”

Carers described one of the barriers to carers being identified is the problem with the term, ‘carer’ – *“people think of paid carers.”* They noted the importance of a mix of visible information being available (e.g. information in waiting rooms, Care for the Carers’ information stands in communities) alongside conversations being initiated with carers to help them identify that they are carers.

“I had seen information about carers, but I didn’t think that was for me.”

“When asked if I was a carer, I used to answer, ‘No, I’m a wife,’ but I’ve been talked into seeing myself as a carer – it was very difficult to accept.”

Carers noted the need to ensure that they are given the right information from the start, and the importance of a consistent message to refer all carers to the Carers Centre, run by Care for the Carers. *“If Care for the Carers is the single point of access then everyone needs to be aware of this, and giving out their information.”*

2. Effective services and systems

Carers identified record-keeping as a key area that needs to be addressed in order to make services and systems more effective, and carers identified the possibility of recording carers on Summary Care Records as one clear method to consistently identify carers for all practitioners working with the carer or the person they care for.



“GPs could add something to the carer’s record so that carers can be easily identified.”

Carers felt that forms which only allow space to record the carer’s contact details, but not their relationship to the person they care for, work against carer identification, and they reinforce the negative emotional impact through loss of identity.

“I’m not ‘just’ a carer – I’m a wife, parent, or brother as well.”

Social prescribing was recognised as a good opportunity to identify and support carers when used well, but it was noted that the Carers Social Prescription is not regularly utilised by health practitioners. It was noted that the Clinical Commissioning Groups have an important role to play in improving this picture.

“Social Prescription is still unknown to many carers and professionals so it is underused.”

“We need to improve the social prescribing pathway and make it the norm for GPs to refer carers to Care for the Carers.”

“The CCGs should ensure GP surgeries recognise and support carers.”

Whilst there was an awareness of services being overloaded, there was a general consensus that *“information sharing between NHS departments is still not good,”* and that this makes caring difficult.

“I often hear different things from different people.”

“You often have to repeat yourself.”

“Communicating across borders such as between East Sussex, Kent and West Sussex makes things even more difficult, as there’s often ‘siloed’ funding.”

Some examples of joined up systems were cited, including a cottage hospital providing a personalised care package which was followed through, and a hospital setting showing flexibility by enabling someone with dementia to be seen on time, rather than having to wait for hours, which was in turn positive for the carer.

Carers supported the proposal to develop the East Sussex Carers Card as a Carers Passport with a visible lanyard so that carers can use it as a tool to identify themselves as a carer in health and social care settings, but noted that training would be needed to help health and social care practitioners to recognise what it means. It was also suggested that Care for the Carers’ contact details should be included on the lanyard, so that professionals know who to contact when they come across other carers.

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 being ignored and excluded, and this having a negative impact on the care plan.

“I would like the agencies to recognise my expertise rather than seeing me as a pushy parent – carers are the experts in what the person they’re caring for needs.”

“GP’s need to take carer views more seriously.”

Perhaps unsurprisingly in the current context of financial austerity, carers made the point that the treatment of the people they care for, or failure by services to give them the right support, hugely impacts on the carer.

“A massive help would be if the person I care for received the proper treatment he needs – that’s what makes a carer’s life a bit easier.”

3. Reducing the negative financial impact of caring



Carers described the negative financial impact of caring.

“It’s a hard struggle as a working carer.”

“I had to go back into work at a lower level just to get money in.”

“The financial impact of caring is felt more by single people, particularly women, as they often spend their whole life caring then lose every benefit they had when the person they cared for goes into care.”

Carers suggested a range of ways to mitigate the negative financial impact of caring.

“Discounted bus travel should be available for carers at any time of day, and whether they are travelling with the person they care for or not.”

“Having lots of agencies based in one community venue helps – so you don’t have to travel to each of them individually.”

“Pay people their benefits quickly so they don’t get into debt.”

“The monthly payment of Universal Credit means the person I care for spends it straight away, so I often end up having to pay his daily living costs out of my limited income. They need to make weekly payments instead.”

“Home visits by the DWP would help for people who can’t get out.”

Carers highlighted the disparity between the significant volume of work that carers undertake and the money paid out through Carers Allowance.

“They should look at what unpaid carers do and notice what they save the country, compared to the cost of paid care.”

“It’s dreadful that there’s no Carers Allowance for pensioners – such an insult.”

4. Breaks from caring

Carers confirmed that they often find it difficult to get a break, as a result of a range of barriers.

“It’s still hard to get a break.”

“I never get a holiday.”

“There are less places to access respite, with Day Care centres closing.”



Carers described the support they need to manage the complex feelings of guilt they experience when taking a break if they do get the opportunity to do so, and the barriers posed when the person being cared for is resistant to alternative care being provided.

“I used to feel terrible, but I realised I had to have a break.”

“You feel guilty – there’s a pull from the person you care for.”

Carers also described the benefits of having breaks from their caring role – *“The Roffey Park carers weekend was the best 24 hours ever! Just what I needed”* – along with a positive example of being supported to take a break – *“Adult Social Care Occupational Therapy service offered a great response with care agencies for me to get a break.”*

Carers identified their need for statutory services to support them in taking breaks.

“It’s hard to get help from the district nurses, there needs to be change there.”

“East Sussex should fund more activities for carers. Brighton and Hove City Council fund an Introduction to Mindfulness course and other activities.”

5. Carer support and engagement



Carers re-affirmed how important the support they receive from Care for the Carers and other support services is.

“Care for the Carers has been a godsend.”

“You get low as a carer. The support helps you start feeling positive again.”

“It’s important knowing you’re not alone – you become a club of people who understand.”

“When I’m low, I know I can call Care for the Carers and get a friendly response.”

Carers highlighted the difficulties they face in finding out about the support available to them, reinforcing the need for the single access point for carer services which has been incorporated into the new East Sussex Carers Centre model that launches in October 2019.

“I didn’t know about Association of Carers’ sitting service until today.”

“There should be clear routes to find out about services.”

“We need information about all services in one place.”

“A booklet with all service information in would be very helpful.”

“Community services need to come together more and link up to provide services.”

Recommendations

The discussions held at the August 2019 Carers Voices Forum built upon the priorities identified at the February 2019 Carers Voices Forum, in order to equip partners with a better understanding of what local carers say is necessary to achieve a carer-friendly East Sussex. **Carers strongly endorsed the need for a cross-sector plan or strategy in East Sussex to bring about necessary change.**

Statutory and voluntary sector partners should therefore consider the feedback detailed in this report when developing a shared plan, to address the following carer priorities:

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Next steps

The key findings and recommendations from the August 2019 Carers Voices Forum will be presented at a range of strategic meetings, shared with key decision-makers, partners and all who attended the Forum, 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 and at Care for the Carers' Annual Carers Voices Conference.



September 2019