CARERS FORUM

FEBRUARY 2019

Carers Voices Today

“A very informative and busy day with opportunity to discuss my concerns and opinions on various matters.”

“The views we capture today – about what matters to you, what services you value, and what needs to change – are more important than ever before.”

Care for the Carers
Carers Forum February 2019

Carers Voices Today

Acknowledgements

Care for the Carers would like to thank all who contributed to making the February 2019 Carers Forum a success – Remploy for providing sponsorship, colleagues and partners that planned and delivered the workshops and speeches, those that supported marketplace activities, Care for the Carers colleagues who worked hard to ensure the day ran smoothly, and the carers themselves who shared so openly their experiences, opinions and ideas.

With thanks to our funders:

With thanks to our sponsors:

Executive summary

Introduction

The Carers Forum, held on 20th February 2019 at St Catherine's College, Eastbourne, focused on the theme, ***Carers Voices Today***. Attended by 56 carers and 9 people they care for, along with Care for the Carers staff and 23 other 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 incorporated keynote speakers representing the NHS and the Care Quality Commission, a launch of a series of short films depicting carers' stories, market place stands providing information and support to carers from a range of local services, and workshops focused on consulting with carers about the key themes detailed in the Government's Carers Action Plan.

In addition to the forum itself, carers who were unable to attend on the day were invited to contribute through an online survey and discussions held at several carers groups. In total, 110 carers and people they care for and 23 professionals contributed to the findings described in this report, including 16 young adult carers.

Key findings

Overall, the following key messages came through from carers and professionals:

- Carers often **feel under-valued and go unrecognised**, with young adult carers in particular reporting feeling ignored by statutory services.
- Carers are **not routinely offered information or support** by Health and Social Care practitioners, and there are many missed opportunities for carers to be identified and referred for support from carer services.
- **Services and systems are not consistently working together effectively** to meet the needs of carers in East Sussex.
- Many carers **face significant financial hardship** as a result of their caring role, compounded by poor responses from employers and a welfare benefits system which disadvantages them.
- Carers find it **increasingly difficult to get a break from their caring role**, and this impacts negatively on their health and wellbeing.
- Carers hugely **value the support provided by Care for the Carers**.

Recommendations

Carers should be routinely identified by Health and Social Care practitioners and community organisations and offered referral to information or support. Care for the Carers will support this by working with partners at a strategic level to achieve routine carer identification, delivering Carer Awareness Training to a range of organisations, promoting awareness of the support available to carers, acting as the single point of access for carer support, and developing and maintaining effective referral pathways with key partners.

Services and systems should work better together to meet the needs of carers in East Sussex. Care for the Carers will support this by ensuring that carers' experiences and views are at the heart of influencing local service and system development, developing effective referral pathways, and working with carers on an individual basis to help them to successfully navigate the systems and services impacting on their caring role.

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. Care for the Carers will support this by working with national charities Carers UK and Carers Trust to lobby to achieve change and by seeking to influence local employers and benefits agencies to develop carer-friendly policies and practice. We will also work with carers on an individual basis to help them to access grants and benefit advice in order to maximise their income.

Carers need to be given a range of opportunities to take time off from their caring role. Care for the Carers will support this by continuing to offer a range of activities and carers groups which give carers positive breaks from their caring role, and by working in partnership with local respite services and commissioners to ensure continued respite provision.

A range of carer services should continue to be made available in East Sussex. Care for the Carers will seek to ensure that carers continue to have access to a range of high quality carer support and engagement opportunities across the County, acting as the single point of access for carer support.

Next steps

The key findings and recommendations from the February 2019 Carers 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.

Following these activities, an updated version of this report, which reflects the actions undertaken and agreed, will be shared widely.

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 February 2019 Carers Forum was ***Carers Voices Today***, in response to this 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, sharing carers' stories, 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 in order to ensure there was sufficient focus on hearing carers' voices at the event, the format of the workshops was different to previous Forums. Rather than incorporating information sharing from partners alongside consultation opportunities, the workshops at this forum solely focused on consulting with carers (about the key themes detailed in the Government's Carers Action Plan), and lots of rich feedback was gathered as a result. This change was positively received by carers – *"I liked the new format; it worked really well."*

The event was held at St Catherine's College in Eastbourne. This choice of location in the Eastbourne, Hailsham and Seaford 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 56 carers and 9 people they care for. 100% of carers completing the evaluation question giving an overall rating of the Forum assessed the day as good or excellent. For more information please see Appendix A.

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 23 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, Coastal Wellbeing, Connecting4you & East Sussex Better Together, Cranstoun – East Sussex Family & Carers Team, East Sussex County Council (ESCC) – Safeguarding Development Team, ESCC – Support with Confidence, Healthwatch, Heringtons Solicitors, High Weald, Lewes & Havens Clinical Commissioning Group Medicines Management, ICE Project, Parkinsons UK, Remploy, South East Advocacy Projects, St Michaels Hospice, Sara Lee Trust, St Wilfrid's Hospice, Southdown – People in Partnership, Southdown – East Sussex Community Network, Southern Water & South East Water Affordability Teams, Sussex Partnership NHS Trust, and Time for Dementia.

The best thing about the day was…

"…gaining information from various groups in the market place.

"…the Market place. Got a lot of help."

"…being able to share and pick up information about services I didn't know about"

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. Jo Egan, Care for the Carers' Director of Services noted, *"The Forums are here to strengthen the evidence base regarding what [carers] need and want, so that services are developed with a better understanding of what it means to be a carer. Together we are stronger in improving the experience of being a carer in East Sussex, and this is more important now than ever before."*

The best thing about the day was…

"… meeting other carers, wonderful time […] to catch up and share news, concerns, happy and sad news."

"…meeting other carers I have not seen recently."

Keynote speakers

Care for the Carers' CEO, Jennifer Twist, introduced the day, shared information about the organisation's funding position, its 30th Anniversary celebrations and the Government's Carers Action Plan. Jo Egan, Care for the Carers' Director of Services, emphasised the focus of the day being about hearing and amplifying carers' voices, gave feedback about learning from previous Carers Forums and the organisation's Annual Survey, and introduced the *Carers' Words, Carers' Lives* Writer in Residence initiative, from which four new films were shown through the morning.

Keynote speaker, Ashley Scarff, Director of Partnerships & Commissioning Integration, Sussex NHS Clinical Commissioning Groups, spoke about the NHS Long Term Plan, reflecting on carers' experiences and roles within the national, regional and local strategic pictures.

Geraldine Matthews, Remploy's Expert by Experience, informed carers about the role of the Care Quality Commission and promoted awareness of the opportunities for carers to influence service improvements by sharing their experiences about services.

Feedback regarding the keynote speeches was positive, with 91% of carers completing evaluations rating them as good or excellent.

"Good speakers - enjoyed it. Very informative."

"All the morning contributors were interesting in their own way."

"[The best thing about the day was the] key speakers."

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

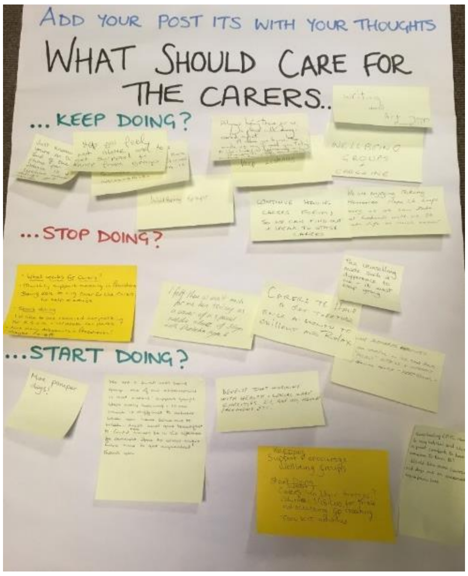
- Social isolation, and the opportunities appropriate social prescribing provides in addressing this.
- A warning against the misuse of social prescribing and the dangers of forcing people to engage with social prescribing against their wishes.
- Statutory systems not being joined up e.g. a battle between primary and secondary care about who is responsible for undertaking a blood test; carers not being communicated with effectively.
- Carers find the Care Quality Commission useful when selecting services.

Carers' stories

At Carers Forums in 2017 and 2018, we premiered films showing carers' stories, produced through the Care for the Carers' Writer in Residence initiative, *Carers' Words, Carers' Lives*. Following excellent feedback from carers about this component of the day, at this Forum four new films were premiered. The films are part of a set of 12 short films profiling carers' stories and a new creative writing workbook, launched at the Forum and the result of the third phase of the Writer in Residence initiative, funded by the Heritage Lottery Fund. Focusing on carers from a range of backgrounds and in different caring roles, the powerful films were shown through the morning, and ensured that carers' voices were a strong thread running through the whole day. The films are available to view at www.cftc.org.uk/Blogs/carers-stories/Category/carers-stories-and-writing

"Each carer's voice coming out of silence speaks to the world on behalf of the many carers whose lives may be unheard. Each voice represents the bravery and integrity of the many." *Evlynn Sharp, Writer in Residence*

"[The best thing about the day was the] watching the videos of carers experiences and hearing other carers experiences."



Key questions

Introduced during the keynote speaker session, the Forum featured a request for carers to engage with some 'key questions' – *What works for carers?* and *What should Care for the Carers keep doing/stop doing/start doing?* – to capture carers views through a different methodology, in addition to the opportunity to give their views at workshops and in the marketplace. The questions were prominently displayed on flipcharts in the main hall where the forum was held, and carers were encouraged to record their views on Post-It notes throughout the day. 26 comments were recorded through this method.

Workshops

Carer workshops were facilitated by Care for the Carers' staff, with the aim of gathering carers' views on what matters to them, exploring four themes identified within the Government's Carers Action Plan, as follows:

- **Services and systems that work for carers**
- **Employment and financial wellbeing**
- **Supporting young carers and young adult carers**
- **Recognising and supporting carers in the wider community and society**

Overall the workshops received very positive feedback from carers completing evaluations, with 97% of respondents stating that the workshop met their needs.

The workshop which had the highest attendance was *Services and systems that work for carers*, and no carers signed up for workshop on *Supporting young carers and young adult carers*, so the decision was taken to run the workshop on *Services and systems that work for carers* in two separate groups in order to accommodate all the carers who wanted to attend. The workshop on *Supporting young carers and young adult carers* was however held at the Young Adult Carers Group on 7th February 2019, to ensure that feedback was obtained on this theme.

The workshops ran for an hour, however, several carers commented on wanting more time for workshop discussion, so allowing more time for the workshops will be considered when planning for the next Forum.

Running alongside the carer workshops was a workshop for professionals, facilitated by Sam Tearle, Head of Strategic Commissioning – Housing and Support Solutions, ESCC, and Tamsin Peart, Strategic Commissioning Manager – Adult Social Care, ESCC. This workshop also focused on *Services and systems that work for carers*, and 16 professionals attended this to share their experiences of working with carers.

What carers said – key themes

During the workshops, through evaluation forms, in conversation throughout the day, and in the wider reach to carer groups and online, carers shared their personal experiences of the day-to-day reality of being an unpaid carer in East Sussex. Below are the key themes that emerged through the various feedback methods used.

Overall, the following key messages came through from carers and professionals:

- Carers often **feel under-valued and go unrecognised**, with young adult carers in particular reporting feeling ignored by statutory services.
- Carers are **not routinely offered information or support** by Health and Social Care practitioners, and there are many missed opportunities for carers to be identified and referred for support from carer services.
- **Services and systems are not consistently working together effectively** to meet the needs of carers in East Sussex.
- Many carers **face significant financial hardship** as a result of their caring role, compounded by poor responses from employers and a welfare benefits system which disadvantages them.
- Carers find it **increasingly difficult to get a break from their caring role**, and this impacts negatively on their health and wellbeing.
- Carers hugely **value the support provided by Care for the Carers**.

Each workshop generated discussions about caring in East Sussex, with specific themes emerging as follows:

1. Services and systems that work for carers

Carers and professionals reported **mixed experiences of health and social care systems and pathways**, with some describing positive responses to carers, such as GPs identifying carers and **referring them for support immediately** following diagnosis, and others describing **disjointed responses and carers having to battle** to get the support which they or the person they care for need.

"I feel valued by my doctor. My doctor knows me and my partner. There's a swift response and it's a good surgery".

"There was a lack of coordination after diagnosis – the paperwork was daunting and I was left to cope – for a long time not being kept informed."

“Rehab services took months to come and see my Mum for assessment. After a long wait, they said that they could not offer anything and closed the case.”

“Identifying and referring carers should be a mandatory part of the contracts for all commissioned services.”

Throughout the workshops there was a strong theme that **carers find it difficult to find the information or support they need, when they need it**, and the reluctance of many frontline services to identify carers or refer them for support.

“At the beginning of the caring role, or at first diagnosis, tell me where to go for help.”

“Caring is a multi-role – researcher, problem solver, organiser.”

“Repeating my story was upsetting, I was in floods of tears. I want one point of contact and access.”

The **barriers to carers being identified** were highlighted, with discussion about carers not always seeing themselves as carers, and this barrier being compounded by a common lack of carer awareness amongst frontline staff.

“It can be a long time before you realise that you are a carer and it often takes someone else to tell you.”

“Professionals often don’t ask the partners if they are a carer.”

In the professionals’ workshop, **tools for identifying carers** were noted, including the East Sussex Carers Card, and all agencies needing to ‘think carer’ (e.g. accessing Carer Awareness training and identifying every carer they come into contact with, using existing frameworks which encourage carer identification, such as Triangle of Care and the ‘whole family approach’).

Carers gave feedback about the **importance of being valued or recognised by staff within the Health and Social Care system**, but described mixed experiences of this, and many carers reported not having had a Carers Assessment.

“I felt valued for first time when I spoke to Care for the Carers.”

“Carers feels invisible and worthless. You have to make yourself heard.”

“Mum’s Care home valued me – they listened to me about ways to address the issues and involved me.”

“It seems like they don’t want to spend money on the over 75’s, they have written us off.”

Carers noted that **support is often short-term**, and doesn’t cater for the fact that caring is often long term.

“Nobody stays involved – they pick you up then drop you.”

Carers’ **top aspirations for improvements to Health and Social Care Systems** were cited as:

- Easy access to relevant and useful information, proactively given to carers early in their caring role e.g. all Health and Social Care practitioners providing information on support available as a matter of course, automatic direct referrals from GPs to Care for the Carers as soon as a carer is identified or a diagnosis given
- Services listening to families' needs, taking a personalised and holistic approach and not focusing solely on the person being cared for– *"Don't waste time telling me what you think I need - ask me!"*
- Better communication between services and with carers
- A Carers Lead in all health settings
- Available respite care and counselling

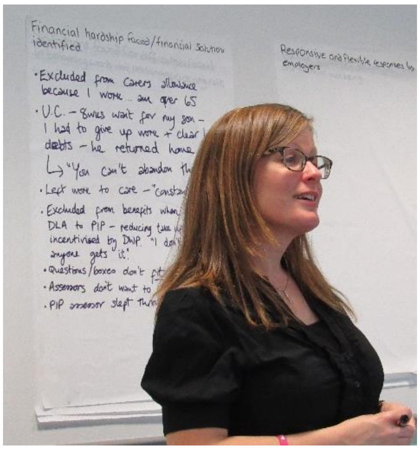
2. Employment and financial wellbeing

Carers shared their experiences of the **significant financial hardship faced as a result of caring**. They described the **challenges posed by a welfare benefit system which is not fit for purpose and neglects to address carers' needs**, noting being doubly impacted as carers by the failure of the benefit system to support the people they care for.

"I had to pay for my son whilst he waited months for Universal Credit to be paid – I couldn't afford it but you can't abandon them, can you?"

"He's had to move back in with me because his benefits were stopped – which puts more pressure on me."

"Assessments for PIP cause extreme stress. My son had to go to Brighton for his assessment, where there was no wheelchair access and no parking, and when we got there we were told that he didn't need to go as he was too incapacitated. He got a 3 year award and then had to go through the whole process again despite nothing changing with his condition."



Carers described the **barriers to accessing Carers Allowance** – being ineligible due to age or working part time – and the low rate which is paid, which reinforces their sense of being worthless.

"I'm annoyed that Carers Allowance stops at pension age, when I'm still caring. It doesn't make sense, as the role becomes more intense with age and you need to buy in more support."

"Carers Allowance is a pittance – it's less than the minimum wage and makes me feel undervalued."

Carers described a **benefits system which fails to respond to the needs of vulnerable people with significant disabilities**.

"It's so hard to get Personal Independence Payment benefit. When they moved my daughter off DLA and she had to apply for PIP, she didn't get it. We had to support her to appeal and go to tribunal and we still didn't get it. It was so stressful."

“The benefits system is based on incentives for staff to award as few benefits as possible. Assessors don’t want to find a disability in a person and look for reasons that they are capable. The criteria are designed to be so impossible to meet that no one can claim – even if they’re really unwell. I don’t know how anyone gets PIP.”

Several carers noted that there are some options to help carers financially – e.g. Attendance Allowance for the person you care for, utility company bill caps and schemes for vulnerable people, Council Tax reductions – and wider carer support available, but **many carers are unaware of their options**, the **information is not volunteered** by the professionals carers are in touch with, and **carers often have to battle** to get what they need.

“We should have people telling us about the benefits, not having to search for information about them.”

“It’s like a secret society and you have to keep knocking the door until someone lets you in.”

“There should be a consultant at the GP surgery telling you where to get everything you need as a carer – as soon as there’s a diagnosis.”

“I’m exhausted by the constant fight to get what I’m entitled to.”

“Everything is a fight. You feel defeated all the time.”

Carers described **inconsistent employer responses to employees with caring responsibilities** because the legal rights for working carers are so limited, with some carers being supported by understanding managers, and others being disciplined for taking time off to care.

“Employers pile on the pressure, having disciplinary meetings – in the end, I had to give up work.”

“I was put off by my employer and won’t ask for Flexible Working as they have treated others badly.”

“My experience with my employer has been positive; my manager is happy for me to take the time off I need for my son’s appointments. I think this is because she knows I’m loyal, as I work a lot of extra hours usually. It’s not the same for everyone – my colleague doesn’t get much support when she needs time off for her caring role.”

Carers described the **difficulties faced in balancing work and performing a caring role**, and several carers had either moved into less secure, part-time or self-employed jobs in order to fit work around caring, or had given up work altogether.

“I had to change to part time work due to the support my son needed.”

“I tried working from home but that didn’t work so I had to give up in the end.”

Carers noted the **negative impact on their identity of giving up work to care**.

"Because carers don't get paid, we aren't valued at all. You don't have an identity which people recognise like you do with other work."

Carers' **top aspirations for improvement to employment practice and financial wellbeing** were cited as:

- Employers should have clear carer policies
- Better employment rights for carers e.g. a right to flexible working hours and paid care leave for carers
- Better Carer Awareness by Department of Work and Pensions staff
- Joined up systems e.g. an automatic link between a GP/consultant diagnosing someone with a disability and the relevant benefits being awarded

3. Supporting young carers and young adult carers

Young adult carers described the **mixed impact of caring on young carers and young adult carers' health and wellbeing**. They cited impacts which were often negative (back and knee pain, existing health issues being exacerbated, lack of sleep, depression, eating disorders, self-harm, anxiety, panic attacks, suicidal thoughts, the carer's own needs being neglected – *"You put yourself last"*, and being unable to focus on a 'normal' life – *"It doesn't matter what you're doing, you're always thinking about what's going on with the person you care for"*) but sometimes positive (increased patience, a sense of humour, resilience – *"You become a fighter"*, and empathy – *"I'm more considerate"*).

Young adult carers reported having been **identified by social services, schools and colleges, paramedics, friends and family, and some had self-identified** as carers, but there was agreement that **young carers often go un-identified**.

Overall, they reported experiencing a **lack of respect towards young carers and young adult carers by statutory organisations** because they are not kept informed as the primary carers, and at times young carers are ignored completely.

"When I was 14, my mum was taken into hospital in an emergency. Nobody checked up on me or made sure I could look after myself – I had to contact friends and family myself to get the support I needed."

Young adult carers felt strongly that further education **colleges fail to respond flexibly to young adult carers' needs**, and their caring role is often a barrier to them succeeding in further education.

"My tutor threatened to kick me off my course because my attendance was at 89% and they wanted it to be at 90%."

"I just felt that the tutors were belittling my issues."

"Tutors told me to lie to my mum and not tell her I was going to be late home from college – they didn't understand how much that would increase her anxiety."

"Your support depends on the tutor and their understanding of caring and your caring situation."

"I was kicked off my course because I had mental health issues and was finding the course difficult."

Young adult carers emphasized the **need for peer engagement and support for young carers**. Several young adult carers offered to mentor young carers and support the identification of young carers in local schools.

Suggestions regarding **where to raise awareness of young carers and young adult carers** included social and print media, TV (e.g. Blue Peter, CBeebies), radio (e.g. Heart), YouTube, billboards, cartoons/animations (e.g. Cartoon Network), cinema advertising, Sky, Netflix, local gyms, restaurants (e.g. McDonalds), theatres, piers, pubs, and schools.

4. Recognising and supporting carers in the wider community and society

Carers described **some positive experiences of community services being flexible and responsive to the needs of carers** and the people they care for, but noted that **practice is inconsistent**, and largely focused on access for people with visible physical disabilities rather than directly supporting carers or responding to hidden disabilities.

"Sheffield Park has mobility scooters, including tandem scooters so that carer and the person they care for can go round together."

"The onus is often on me as the carer to ask for accessible facilities, rather than them being volunteered."

"Shopmobility is useful for getting out and about with the person I care for."

"A lot of hospitality places, such as restaurants and hotels, have accessible facilities just to tick a box – they're not really accessible. Some disabled toilets have stairs on the way to them, and some disabled rooms in hotels are not easy to get into or cost more than other rooms."

Carers generally expressed a **desire to be made more visible** as carers, with some supporting the idea of using cards, bracelets, badges or lanyards to identify them as a carer, run along similar lines at the Autism Stress Alert Card. Some carers liked the idea of being able to discreetly identify themselves with information slips that they could pass to staff in community settings, in order to alert them to their needs in caring for someone with a hidden disability or health condition.

Carers reported that there is an **absence of respite** available to them, and this impacts negatively on their health and wellbeing. They reported finding it hard to get a break, both in terms of arranging respite and in finding respite that is available and suitable to keep the person they care for comfortable and content. Carers shared some negative experiences of respite provision, including the respite provider losing the client's property and respite only being available on a short-term basis.

Suggestions regarding **where Care for the Carers should target to promote awareness** of its services included GP surgeries, supermarkets, community venues, places of worship, libraries and leisure centres, TV and radio, volunteer organisations, and local publications. It was noted that staff awareness is central to making carer-friendly communities – *"It's good people that generally make the difference, not necessarily systems, institutions or facilities."*

Findings from our key questions

The feedback on our key questions echoed many of the themes raised in the workshops. Responses to the question, "***What works for carers?***", were noted as follows:

- *"It helps to join with others and feel listened to."*
- *"Knowing just what's available for carers in terms of financial, home (utility reduction) council tax, emotional help, support groups, advance care planning and so on."*
- *"Having flexibility at work. I worked 37.5hrs per week, but also care for my mother. Balancing both can be challenging. I have now dropped my hours to 30 and helps greatly with GP appointments etc."*
- *"As a 61 year old woman, I am a full time carer, no job and no income. I rely on my husband for all finance. I feel totally deprived. I have to wait for my pension another 4 years, as a carer I feel this is wrong."*

Responses to the question, "***What should Care for the Carers keep doing/stop doing/start doing?***", gives Care for the Carers useful feedback for future service planning, and were noted as follows:

Keep doing:

- Support and advice – *"Just knowing you are on the end of a phone for advice is a lifeline when things get tough"; "Keep giving us information"; "Just being a* *friendly voice at the end of the phone is helpful. Someone to turn to who understands the challenges that carers face."*

- Carers groups – *"So very helpful and also a great comfort to have someone to turn to!"; "Help you feel not alone and to get support and advice from group."*
- Carers Forums – *"So we can find out and speak to other carers."*
- Counselling – *"Thank you for the counselling I didn't realise that I needed it but I clearly did!"*
- Activities, e.g. spa days, cream teas, cinema and theatre trips
- Evening carers group
- Carer's Card
- CareLine

Start doing:

- Make more carers aware of why they need to attend events like this – promotion needs to clearly set out what the purpose of the event is
- Offer a legal advice service which provides legal representation regarding carers rights
- More weekend and evening activities for working carers
- Offer other activities such as pain management, massage, Reiki, dancing, relaxation, and coach trips
- More joint working with other charities that come into contact with carers (e.g. Age UK, Mencap)
- Offer more carers groups, and some in the afternoon rather than the morning
- Continue to sign up more businesses to offer Carers Card discounts (e.g. Co-op, other local hospitals)
- Advise on trade people to use who are trustworthy

Stop doing:

- Consider letting carers attend the Carers Information and Advice Groups indefinitely rather than supporting them to move on to a peer-led Carers Wellbeing Group after 12 months.
- *"Nothing, you do a terrific job."*

Recommendations

Carers should be routinely identified by Health and Social Care practitioners and community organisations and offered referral to information or support. Care for the Carers will support this by working with partners at a strategic level to achieve routine carer identification, delivering Carer Awareness Training to a range of organisations, promoting awareness of the support available to carers, acting as the single point of access for carer support, and developing and maintaining effective referral pathways with key partners.

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A range of carer services should continue to be made available in East Sussex. Care for the Carers will seek to ensure that carers continue to have access to a range of high quality carer support and engagement opportunities across the County, acting as the single point of access for carer support.

Next steps

The key findings and recommendations from the February 2019 Carers 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.

Following these activities, an updated version of this report, which reflects the actions undertaken and agreed, will be shared widely.

Detail of attendance and overall evaluation APPENDIX A

The event was well attended by a mix of people, including 56 carers and 9 people they care for. 11 of these carers and 3 people they care for had not attended a Carers Forum before. 10 carers came from High Weald, Lewes and Havens Clinical Commissioning Group (CCG) area, 29 from Eastbourne, Hailsham and Seaford CCG area and 24 from Hastings and Rother CCG area. We seek to rotate the location of the Forums between the three CCG areas, so it is anticipated that there will be a higher attendance from carers in the north of the county when we hold the next forum in the High Weald, Lewes and Havens CCG area.

19 men and 46 women attended. Five of the carers' that gave their age were under 55 (no age was recorded for 3 carers). 32 other carers' booked a place but either had to cancel in advance or could not attend on the day.

In addition to the event itself, we broadened the reach and accessibility of the dialogue by running an online survey on the 'key questions' and by holding discussions regarding the workshop themes or 'key questions' at the following Carers Groups:

- Young Adult Carers Group 7.2.19
- Evening Carers Information and Advice Group (Eastbourne) 26.2.19
- Herstmonceux Carers Information and Advice Group 4.3.19
- Heathfield Carers Information and Advice Group 5.3.19
- Crowborough Carers Information and Advice Group 5.3.19

As a result, **a further 36 carers contributed their views**, making the findings more representative of the wider carer population in East Sussex and meaning that a total of **110 carers and people they care for and 23 professionals contributed to the findings described in this report**, including 16 young adult carers.

Of those that attended on the day, 35 carers completed evaluation forms, comprising a 54% response rate. 100% of carers completing the evaluation question giving an overall rating of the Forum assessed the day as good or excellent.

What carers said about the day:

"I felt overwhelmed by the support and information on offer. I was feeling down as my husband has Alzheimer's and my son schizophrenia, now I feel on cloud 9!"

The best thing about the day was…

"…watching the videos of carers experiences and hearing other carers experiences."

"..the Market place, fact finding. Identifying the future gov. action plan for carers."

"…the relaxed feel of the day."

"Thank you for a very informative, caring and helpful day. It was the first time I've attended anything like this in my 4 years as a carer. I met lots of like-minded people. It felt good to be surrounded by such dedicated and inspirational people. […] I've even joined a group of carers meeting once a month this would not have been possible without the […] forum."

Care for the Carers had 16 staff in attendance at various points during the day, ensuring the day ran smoothly, facilitating stands and highlighting the range of services and opportunities available to carers across the county.

Some difficulties arose with the venue on the day – specifically technical issues with the microphones, unplanned building works on site, and a late alteration to the venue's access arrangements resulting in a less direct entry route for forum attendees. Most feedback on this demonstrated an understanding that the issues were outside of Care for the Carers' control, but will nonetheless inform planning for future events.
"Tech issues were unfortunate. Really felt for the CftC team as they had put so much effort in."

12 professionals completed evaluation forms to give their views on the event. Feedback received was overwhelmingly positive, with all the professionals completing the evaluation forms rating their overall experience of the Forum as very good or excellent.

What partners said about the day:

The best thing about the day was…

"…meeting and talking with carers new and old and networking with partner organisations. Loved the films, really soulful work and wonderful to hear carer voices."

"…connecting with other professionals and carers. Community and connection."

March 2019