




Supporting Carers in East Sussex

“A brilliant day, wonderful film and poetry, caught up on information and knowledge about the jigsaw of services and what help is available for carers!”

SPRING CARERS FORUM 2018

Planning for the Future

Care for the Carers Spring Carers Forum 2018

Planning for the Future

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Care for the Carers would like to thank all who contributed to making the spring 2018 Carers Forum a success – partners that planned and delivered the workshops on the day, 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.

Thank you.



Introduction – setting the scene

Carers often worry about the future – what will happen to them and the person they care for if their circumstances change. The theme chosen for the spring 2018 forum was **Planning for the Future**, in response to feedback from carers at previous Carers Forums, through our Carers Voices Network, and through other contact with carers, where carers regularly express concerns about the issues to consider when planning ahead regarding their caring role.

Now an established and popular event for East Sussex carers and the organisations who seek to support them, the format of the day mirrored that of previous Carers Forums, consisting of opening speeches, opportunities for carers to visit the marketplace, a film screening and poetry reading over lunch, and workshops facilitated by a range of organisations. The day was structured to help carers think about some of the options available, gain support from local organisations and share their experiences and views.

The event was held at Bexhill College, which received positive feedback from carers in terms of accessibility and comfort. This choice of location in the Hastings and Rother 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 in attendance, notes from workshops which captured carers' views, experiences, concerns and ideas and any additional feedback received after the event. An anonymised data pack is available on request. 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



80 carers and 20 cared for people attended the event.

17 of these carers had not attended a Carers Forum before, which is the highest number of carers newly attending a forum to date. 16 carers came from High Weald, Lewes and Havens Clinical Commissioning Group (CCG) area, 28 from Eastbourne,

Hailsham and Seaford CCG area and 36 from Hastings and Rother CCG area. The number of carers from the Hastings and Rother CCG area was over double those attending the autumn 2017 forum (held in Lewes), demonstrating the importance of varying the location of the forums.

23 men and 57 women attended. Only five of the carers' that gave their age were under 55 (although no age was recorded for 9 carers). 18 other carers' booked a place but either had to cancel in advance or could not attend on the day.

A minibus was provided from Peacehaven, which 9 carers utilised, and the venue was selected on the basis of its accessible location on public transport routes from Eastbourne and Hastings.

Of those that attended 56 carers completed evaluation forms on the day, comprising a 70% response rate. 95% of carers completing the evaluation gave an overall rating of the forum as very good or excellent.

What carers said about the day:

“Whole day was amazing – this was the first time we have been to a forum and would come again.”

“[The best thing about the day was] the workshops and the market place, information and hearing other carers views.”

“[The best thing about the day was] the whole atmosphere - such a lot of love and care in the room. Very supportive approach.”

What partners said about the day:

“Very well organised and supported by CftC...Excellent and diverse range of resources both in the marketplace and workshops. Overall, a fantastic resource for carers.”



Workshops were facilitated by 20 practitioners from 15 different partner organisations (more detail below) and 29 marketplace stands from Care for the Carers' partner organisations were available for carers to visit, share experiences and gather information. **Services represented** on the day included:

Age UK East Sussex, Association of Carers, C.P.J. Funeral Directors, Community Pharmacy Surrey & Sussex, Connecting 4 You, Cranstoun – East Sussex Family & Carers Team, Eastbourne Law, East Sussex Better Together Alliance, ESCC Integrated Continuing

Heath Care Team, ESCC Scam Awareness, ESCC Support with Confidence/Care Provision, Hastings Advice & Representation Centre, Hastings & Rother Cancer Awareness Project, Headway, Healthwatch East Sussex, Heringtons Solicitors, Improving Carer Experiences (ICE Pro), Intelligent Health - Beat the Street, POhWER Advocacy, Rainbow Alliance for Hastings & Rother, St Augustine's Foundation for Excellence (SAFE), St Michaels Hospice, St Wilfrid's Hospice, SCDA Isabel Blackman Centre, Southdown, Stroke Association & Community Stroke Rehab Team, Sussex Partnership NHS Foundation Trust, and Wealden Citizens Advice.



35 professionals completed evaluation forms while others posted on social media or emailed after 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.

“I just wanted to reiterate how wonderful yesterday's forum was. It is such a privilege to be invited and to co-facilitate workshops. What an honour to hear carer experiences and hopefully by listening to these experiences, we can further shape our services to meet their needs and those of their loved ones.”

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



“Thank you and your team for yesterday, it really was helpful and enjoyable...I felt energised and part of something...A hidden group of super heroes!”

Key elements of the day

Marketplace stands, networking and socialising (on arrival 9.30 am - 11.00 am and over lunch 1.00 pm - 1.45 pm)

This is a very popular part of the day for both carers and partners who staff marketplace stands, and as a result the time slots for this component were extended for this forum.





“Lots of good info for carers at the market place covering a wide range of services.”

“[The best thing about the day was] finding out about all the help available and how to contact them.”

“Really good to be part of such an exciting day.”

Welcome and Introduction to the day (11.00 am - 11.40 am)

Care for the Carers CEO, Jennifer Twist, introduced the day, sharing Care for the Carers’ response to the ESCC budget proposals, outlining our priorities going forward, and setting the scene for us working together in different ways. Teresa Flower, Care for the Carers Strategic Partnerships Manager, spoke about our work to create Carer Friendly communities, by engaging with carers about their views and building strong links with partner agencies to help them to respond appropriately to carers’ needs.

“[The best thing about the day was] all the speakers. Very good presentations in this forum.”

“Great brilliant venue! Brilliant welcome talk by Jennifer. Well done to all at CFTC.”



Workshops (11.45 am - 1.00 pm and 2.15 pm - 3.30 pm)

Workshops were offered across the day with carers choosing in advance both a morning and afternoon session.

Overall the workshops received very positive feedback from carers completing



evaluations, with 84% of respondents scoring the workshops as either good or excellent.

The three workshops which had the highest attendance were *Choosing care provision in East Sussex*, *Looking after your own health and wellbeing*, and *Understanding Continuing Health Care*.

Workshop notes, evaluation forms and carers comments have been used to identify the key issues for carers around the themes explored at this forum. Note takers were allocated to all workshops and their notes are included in a data pack available on request. Anonymous carer evaluation forms were collated and analysed to inform this report and future planning.



1. Lasting Power of Attorney (am and pm)

“Interesting, helpful and consolidated and clarified information.”

Facilitated by Tracey May (Heringtons Solicitors) and Simon Wharne (Carer, professional Sussex Partnership NHS Trust and Carers Lead), these workshops covered the importance of, and practicalities associated with, having a Lasting Power of Attorney (LPA) in place, for both carers and the person they care for, thereby enabling them to decide who they want to make decisions for them about their property and affairs and/or their personal welfare. **24 carers attended these workshops.**

2. Choosing care provision in East Sussex (am and pm)

“Very good workshop with plenty of advice and able to speak and share thoughts. Good presentation just a shame it wasn’t longer.”

Facilitated by Jason Fenton (ASC Operational Development Team), Nancy Godden (Social Worker, ASC), Royston Collins (Community Care Brokerage Manager, ASC), Peter Bond (Senior Practitioner, ASC) and Lyndsey Potts (Support with Confidence), these workshops focused on what care options are available and how funding arrangements are made. **43 carers attended these workshops.**

3. Understanding Continuing Health Care (am and pm)

“Excellent informative and appropriate presenters who were knowledgeable and explained clearly, friendly and positive, good PowerPoints.”

Facilitated by Samantha Simon (Case Assessor, H&R CCG) and Ruth Eldridge (Hospital nurse assessor), these workshops sought to help carers to understand how Continuing Health Care funding decisions are made, and where to go for information and support. **32 carers attended these workshops.**

4. Providing for the person you care for (am and pm)

“It is important to keep introducing information about the legal and financial aspects of being a carer. There is so much to know and do and it’s all so complicated.”

Facilitated by Stephen Pett (Eastbourne Law) and supported by Janet Hardacre (Author of Taking Care of People with Dementia), these workshops addressed the worries carers express about ensuring that the person they care for will be provided for if they are no longer around, by exploring wills, trusts, and lasting power of attorney. **15 carers attended these workshops.**

5. Looking after your own health and wellbeing (am and pm)

“Good to listen about other carers and how they try and cope.”

Facilitated by Josh Broadway (H&R and EH&S CCGs) and John



Worth (Know Your Own Health), these workshops explored the impact of caring on carers' own health and wellbeing and how they can stay well, an issue often neglected by carers as they focus on the health of the person they care for. **32 carers attended these workshops.**



6. Planning for your own future care needs (am and pm)

“Enlightening - some good ideas to take away and build on.”

Facilitated by Bill Hargood (NHS Hastings and Rother CCG), Jane Marquesen (St Michaels Hospice), Sue Lyne (Frailty Team ESBT) and Lisa Sansom (GP Fellow in public health), these workshops encouraged carers to utilise advance care planning as a way of planning for the future for themselves and the person they care for. **18 carers attended these workshops.**

7. Thinking about funeral planning (pm)

“Very informative, well planned, lots of information to refer back to at a later date.”

Facilitated by Paula O'Neill (C.P.J. Field - Funeral Directors) and David Knight (St Wilfrid's Hospice), this workshop explored the various issues for carers to consider in

relation to funeral planning for themselves and the person they care for. **5 carers attended this workshop.**

8. Workshop for professionals - Working together to support carers- practical solutions, Carers Week and beyond

Facilitated by Carole Gregory (Care for the Carers), this workshop aimed at professionals explored ways of working together in the increasingly challenging financial climate, and discussed planning for Carers Week and working together in the future. **17 professionals attended this workshop.**



Film Premiere and launch of Carers' Words, Carers' Lives Postcards (1.45 pm –2.10 pm)

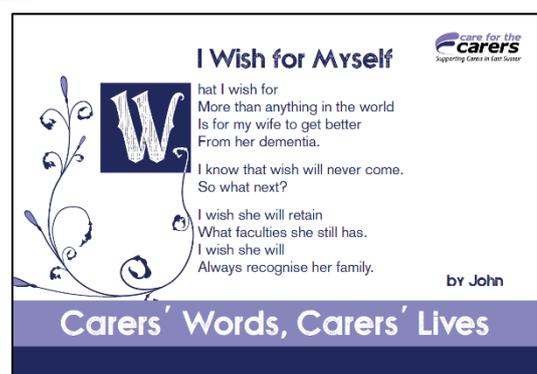
At the autumn 2017 Carers Forum, we premiered three of the films produced through the Care for the Carers' Writer in Residence initiative, *Carers' Words, Carers' Lives*. Following excellent feedback from carers about this component of the day, at the spring 2018 forum another of the films was premiered, focusing on Lea, who shares her experience of caring for her mother who has dementia. The film is available to view at <https://www.cftc.org.uk/blog/leas-story>



The newly-produced film was introduced at the forum by Evlynn Sharp, Writer in Residence, alongside launching and reading some of the poetry created by carers as part of the project. The poems have been published on a set of 6 postcards to be distributed in arts and social venues across East Sussex.

We would like to thank Evlynn, Dan Bridge the film maker and carers for participating in the project and so powerfully sharing their experiences.

“A brilliant day, wonderful film and poetry.”



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. Below are the key themes that emerged, both overall, and during the workshops delivered.



Overall, the following key messages came through from carers during the course of the day:

- **Caring can be overwhelming and challenging**, and this is often not recognised by services
- Carers are really **concerned about the ESCC budget proposals**, but have an **understanding of the situation** and a **willingness to work differently and smarter** with Health and Social Care professionals
- Carers are **concerned about the future of services that the people they care for use**, which if reduced, will have an impact on their caring role

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

1. Lasting Power of Attorney (am and pm)

- These workshops featured lots of questions about individual situations in relation to Lasting Power of Attorney, demonstrating the **continued need for conversations with carers about Power of Attorney** at an early stage in their caring role, and indeed, with the wider population.
- **Carers were keen to obtain practical information** about the process of applying for Power of Attorney (e.g. asking the solicitor what meeting them to discuss Power of Attorney would be like e.g. length/place, cost)

2. Choosing care provision in East Sussex (am and pm)

- Carers spoke of **feeling abandoned in their caring role**, being **expected to become experts overnight**, and **not knowing where to turn**.
- Carers emphasised the **importance of carer services to help them understand their options, provide support and advice, and help carers to negotiate their way through health and social care systems**.
- The importance of **timely, appropriate responses** was highlighted.

3. Understanding Continuing Health Care (am and pm)

- Carers raised concerns about the **lack of choice and control** that carers and the people they care for experience in the context of Continuing Health Care assessments.
- Carers asked specific questions about the **impact of Continuing Health Care funding on welfare benefits** such as Personal Independence Payments; concerns were expressed that any dialogue held with the DWP will lead straight into a reassessment.
- A **fear of “being put into a home”** was voiced.

4. Providing for the person you care for (am and pm)

- Carers acknowledged the **importance of arranging Power of Attorney in advance**, and the positive impact this has on the caring role in enabling their voice to be heard when representing the wishes of the person they care for.
- Carers presented a **range of practical concerns and questions** about individual circumstances, including paying for funerals, funeral plans, and providing for a disabled child in a will.

5. Looking after your own health and wellbeing (am and pm)

- Strong themes came through in this workshop which **highlighted how challenging it can be for carer to maintain their own health and wellbeing** whilst undertaking a caring role.
- Carers described the **anxiety** they often face, the **sense of feeling stuck** in their caring role, and **challenges** they experience which makes them ask, “Should I go or should I stay?”
- Carers spoke strongly about the **negative impact on their health and wellbeing** resulting from:
 - **difficulties with getting GP appointments**
 - **difficulties getting a diagnosis of dementia**
 - **the overwhelming volume of health appointments**
 - **the challenge of advocating for a relative with Learning Disabilities/Autism**
- Carers described the **lack of communication** between NHS departments and a **lack of joined up working** (e.g. between GPs and hospitals), emphasising the **importance of continuity of care**.

6. Planning for your own future care needs (am and pm)

- These thought-provoking sessions helped some carers present to realise that they **had not considered what might happen in the event that they were no longer able to care**.

7. Thinking about funeral planning (pm)

- Carers asked **specific questions about funeral planning**, regarding practical considerations, financial planning, and dignity.

8. Workshop for professionals - Working together to support carers- practical solutions Carers Week and beyond

- Professionals emphasised the **importance of staying connected** and working together in the challenging climate.
- Professionals expressed a **strong appetite for more of this kind of event**.

Hints and tips for carers emerging from workshops

In addition to capturing carers' views and experiences, the workshops also conveyed useful information for carers, key points of which are detailed below.

Lasting Power of Attorney

- There are two types of Lasting Power of Attorney (LPA) – one relating to finances and the other to health and welfare. Everyone is encouraged to consider setting up LPAs as they are a good way of influencing the way you are treated in the event that you lose capacity, and those who do not have an LPA in place and lose capacity face a much more complicated and costly court process to appoint a deputy.
- You can apply for an LPA independently online, through www.gov.uk/power-of-attorney, or through a solicitor (there are some solicitors offering discounts through the East Sussex Carers Card).
- The cost to register each LPA is £82, but the fee is reduced or free for those receiving benefits or on a low income.

Choosing care provision in East Sussex

- The ESCC Brokerage Team (01323 464060; brokerage@eastsussex.gov.uk) is available to support carers with choosing care provision in East Sussex. Even carers who have income/savings over the financial threshold (£23,250) have the same rights as other carers to an assessment, support from the brokerage team, and support developing a care and support plan.
- The financial assessment is based on the income/savings of the person requiring care and support services, not the carer. Carer services are not chargeable.

Continuing Health Care

- The areas of care looked at during a Continuing Health Care (CHC) assessment are referred to as 'domains'.
- Once the assessment has been received, the response times are as follows:

○ Community based care (at home)	28 days
○ Acute hospital care	14 days
○ Residential home care	14 days
○ Fast track	24hrs

Health and wellbeing

- The Five Ways to Wellbeing (Connect, Get active, Keep learning, Give to others, and Take notice) were developed by the New Economics Foundation to help people to consider the steps they can take to improve their mental wellbeing. More detail can be found on www.gov.uk/government/publications/five-ways-to-mental-wellbeing

- Sources of health and wellbeing services information:
 - ESCIS East Sussex Community Information Service www.escis.org.uk
 - Help My GP www.sussexhelpmy.nhs.uk
 - NHS Choices
www.nhs.uk/NHSEngland/AboutNHSservices/doctors/Pages/NHSGPs.aspx

Advance care planning

- Carers are encouraged to consider Advance Care Planning (ACP) as a tool to help guide decisions when mental capacity is compromised or health issues change with time.
- Advance Care Plans can be quite broad in what they cover, and can include specific preferences regarding how a person wishes to maintain dignity or remain stimulated.
- Developing an ACP is a shared journey between family, healthcare professionals, friends etc., and starting the conversation as early as possible is key to developing an effective plan.
- There are a range of ACP templates available, and useful information and resources can be found regarding ACP on the following websites:
www.compassionindying.org.uk
www.dyingmatters.org/overview/resources
www.justice.gov.uk/guidance/protecting-the-vulnerable/mental-capacity-act
www.publicguardian.gov.uk
www.ageuk.org.uk/home-and-care/home-safety-and-security/lifebook/

Funeral planning

- Funeral plans, if paid for at the start, are inflation proof, except for the costs not set by the funeral director, such as cremation costs. Many plans can be paid in instalments to break down the cost.
- It is best to read through the detail of a funeral plan carefully, as it should tell you all of the terms and conditions, as well as what your plan will and will not cover. Some funeral plans can be moved from one location to another, but others cannot.
- St Wilfrid's Hospice and CPJ Field advised carers to put trust in personal recommendations and word of mouth when selecting a funeral director. They noted that a good funeral director should centre the conversation around wishes for the funeral.
- The DWP can provide means tested funeral grants for people with no funds to pay for funeral costs, and there are also a number of grants available through charitable trusts.

Next Steps

This report, and information provided at the forum, will be shared with carers, professionals and the wider community with the aim that as many stakeholders as possible are informed about the issues impacting on carers in relation to planning for the future, the impact caring has on unpaid carers and what needs to change to make

East Sussex more carer friendly. The following actions have been initiated or are planned:

- Presentations by Care for the Carers' CEO to strategic decision-makers regarding the key findings from the spring 2018 Carers Forum at:
 - Connecting4You Operational Delivery Group
 - Collaborative Health and Wellbeing Stakeholder Group
- Articles in CareLine magazine (print run of 10,000 copies) will ensure that as many carers as possible, particularly those who were not able to attend the spring Carers Forum, have access to information around planning for the future as shared in forum workshops.
- This report will be shared widely through Care for the Carers e-Newsletter, Carers Voices Network and East Sussex County Council Carers Services Network as well as being available on Care for the Carers website.
- All who attended the Carers Forum (carers and professionals with an email address) will be sent the report and encouraged to share the findings widely.
- Care for the Carers will ensure that key issues from the forum are shared with those who make decisions, commission or deliver services for unpaid carers across the county.
- A full data pack, made up of anonymised feedback from workshops and event evaluation forms, will be available on request to all stakeholders (carers and professionals).
- Information from the data pack and this report will be used by Care for the Carers to add impact and evidence to their work to increase carer awareness and strategic representation of unpaid carers.
- Care for the Carers will continue to offer carer awareness/carers friendly community training, and action planning support, across health, social care and third sector provision, drawing on carer feedback captured at the forum.
- Learning from this forum will inform planning around content and delivery of the next Carers Forum.

