



# AUTUMN CARERS FORUM 2017

**Carers' Rights, Carers' Experiences**

 **care for the  
carers**  
Supporting Carers in East Sussex

*"The whole day was great and really lovely to talk  
to other carers in a supportive environment"*

**Autumn Carers Forum 2017**  
**Carers' Rights, Carers' Experiences**

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*Care for the Carers would like to thank all who contributed to making the autumn 2017 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)

The autumn 2017 Carers Forum location, theme, content and format was planned to build on the success of previous, biannual, countywide, Carers Forums. Decisions were made incorporating feedback from participants' evaluations, learning from engagement with the Carers Voices Network members and discussions with partners who are striving to improve their services for carers across East Sussex.

Understanding and gaining access to their rights is an ongoing concern for the unpaid carers we meet and the forum was an ideal opportunity to explore this with carers from across the county whilst also supporting our work around the National Carers Rights Day campaign in East Sussex. On the day Care for the Carers were encouraging local partners, media contacts and carers to join in the campaign to raise awareness of carers' rights.



This report will briefly record feedback on the day using evaluation forms from both partners and carers in attendance, notes from workshops which captured carers' views, experiences, concerns and ideas and feedback through social media. A data pack will be available containing full notes from workshops and evaluation data spreadsheets. For further information to discuss next steps please contact Teresa Flower, Care for the Carers Strategic Partnership Manager, by email: [info@cftc.org.uk](mailto:info@cftc.org.uk) or by telephone: 01323 738390

## Attendance

In total **91 carers and 10 cared for people attended** the event. 34 of these carers had not attended a Carers Forum before. 49 came from High Weald, Lewes and Havens Clinical Commissioning Group (CCG) area, 35 from Eastbourne, Hailsham and Seaford CCG area and 17 from Hastings and Rother CCG area, highlighting why it is so important to vary the location of the forums.

34 men and 67 women attended. Only five of the carers' that gave an age were under 55 (no age recorded for 18 carers). 45 other carers' booked a place but either had to cancel in advance or could not attend on the day.

Minibuses were provided from Hastings (stopping at Little Common), Peacehaven and Crowborough.

Of those that attended 52 completed evaluation forms on the day with the majority (41) rating the forum as a whole very good or excellent.

Carers' said that some of the best things about the day were meeting other carers, the friendly atmosphere, gaining new information and the supportive environment.

*"Very friendly atmosphere, with well supported Care for the Carers representatives"*

*“A chance to learn new things and meet people who are in similar situations”*



*“Beautiful films! Thank you for a splendid lunch. Chance to meet CftC staff and other carers and friends”*

*“Whole day was great & really lovely to talk to other carers in a supportive environment”*

*“As well as the workshops, being able to talk to others both who I knew and those I hadn't met before about caring”*

### **Workshops were facilitated by**

**18 practitioners** (more detail below) and 26 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 – Scams Prevention, Alzheimer’s Society, Brighton Carers Centre, Brighton & Hove Buses, Brighton & Sussex Medical School, British Red Cross, Coastal Wellbeing, Connecting 4 you – NHS High Weald Lewes and Havens CCG, Department for Work and Pensions – DWP, East Sussex Better Together Alliance**

**Eastbourne, Hailsham & Seaford CCG & Hastings & Rother CCG, East Sussex County Council – Locality Link Workers, East Sussex Family & Carers team – Cranstoun, Headway, Ice Pro – Improving Carers Experience Programme, Imago – East Sussex Young Carers, Macmillan East Sussex Welfare Benefits Advice Service, Motor Neurone Disease Association, Parkinson’s UK, Safeguarding Development Team – ESCC, Southdown Ambitions, St Michaels Hospice, Sussex Community Development Association (SCDA) – Hastings, Sussex Community Development Association (SCDA) – Newhaven, Sussex Armed Forces Network, Sussex Partnership NHS Foundation Trust and Wealden Citizens Advice Bureau.**



31 professionals completed evaluation forms while others posted on social media or emailed after the event. Feedback received was overwhelmingly positive.

*“It was extremely well attended so the promotion and organisation must have been fab! It was attended by a lot of different professionals which is a great offer for carers”*

Guests included The High Sheriff Maureen Chowen with her husband Mr Michael Chowen, Evlynn Sharp Writer in Residence and Film maker Dan Bridge, Peter Simpson, Caring4Sussex Content Director and Care Quality Commission Reviewers Wendy Dixon and Christine Bennett.



Carer for the Carers had 17 staff and volunteers in attendance, ensuring the day ran smoothly, facilitating stands, highlighting the range of services and opportunities available to carers and promoting **Carers Rights Day** activities across the county.

They also encouraged carers to complete a **Carers Rights Survey** which has been shared widely in hard copy and was available online during November 2017.

## Key elements of the day

### Marketplace stalls, networking and socialising (on arrival 9.30 am - 10.30 am and over lunch 12.30 pm - 13.10 pm)

This is a very popular part of the day for both carers and partners who staff marketplace stands, as a result the time slot has been extended for recent forums.



*"The amount of people who approached our stand wanting information and advice helped raise the profile of the Citizens Advice" (Professional)*

### Introduction to the day and presentation of Building a Carer Friendly Community Awards (10.30 am - 11.05 am)



Care for the Carers CEO, Jennifer Twist, introduced the day and then handed over to The High Sheriff, Maureen Chowen, to present awards to six local services who are working with Care for the Carers to become more carer friendly.



The awards were presented to: East Sussex Health Care NHS Trust, Frailty Practitioner Team, Age UK East Sussex Community Navigator Service and Information and Advice Service, Southdown Ambitions Service, NHS Eastbourne, Hailsham and Seaford CCG and Hastings and Rother CCG Engagement Team and Sussex Partnership NHS Foundation Trust. **The appendix at the end of this report** gives a little more detail of the journey they are on to support East Sussex to be a more Carer Friendly County.

## Workshops for carers (AM 11.10 - 12.25 and PM 13.40 - 14.55)



Workshops were offered across the day with carers choosing in advance both a morning and afternoon session. The majority of carers who completed an evaluation form rated the **overall choice of workshops good or excellent** (44 out of 49). Carers' were asked to comment on each of the workshops they attended, and this feedback varied depending on whether the workshop met their expectations or needs.

An issue that was highlighted by both carers and facilitators in a number of workshops was that often carers' just needed the opportunity to talk about the problems they were facing and that the workshop setting, or format, was not the best place for this to be dealt with.

Workshops were jointly facilitated by practitioners from a range of backgrounds and localities. This meant that the format and delivery of each workshop varied. While all facilitators received the same briefing around a balance of content between carers learning about the subject/theme and sharing their experiences and ideas (Carers Voices), in reality, due to the needs of the carers in the groups, this was not how all workshops ended up being delivered leading to marked variations between the amount of carers' feedback recorded by note takers.

**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 the information was recorded on to the CftC database. This information is also part of the data pack available.

During the workshops there were many questions that related to carers individual circumstances but that could equally apply to many others. Some carers were advised to get individual advice, but other issues could be addressed during the sessions and responses can be seen in the workshop notes included in the data pack.

### A. Your rights when the person you care for is admitted to hospital (am and pm)



Facilitated by **Lisa Flindall**, **Paul Lambirth** and **Beverley Mills** from East Sussex Healthcare NHS Trust and supported by **Darragh McEnerney** (Adult Social Care).



These workshops covered the support available to you when the person you look after is admitted to hospital and your rights around information sharing, care planning and hospital discharge. **38 carers attended the workshops and 17 carer evaluations were received.**

### B. Your rights when you are a mental health carer (am and pm)

Facilitated by **Jane Shepherd**, Consultant Psychologist and **Jacqueline Clarke - Mapp** Carer lead, from Sussex Partnership NHS Trust. These workshops offered the opportunity to explore the reality of being a mental health carer and share your experiences of mental health services.

**24 carers attended the workshops and 9 carer evaluations were received.**



### C. Your rights around community based health care (am and pm)

Facilitated by **Sue Lyne**, Nurse Consultant for Frailty & Older People, East Sussex NHS Healthcare Trust, **Emily Smith**, Project Manager – Joint Commissioning High Weald Lewes & Havens Clinical Commissioning Group – East Sussex County Council and **Christine Ketley**, Age UK East Sussex Community Navigator Service Manager.



These workshops offered the opportunity to explore and discuss carers' experiences of healthcare delivery in the community. To identify areas of good practice and areas requiring improvement.

**40 carers attended this workshop and 17 carer evaluations were received.**

#### D. Your rights when end of life conversations are approaching (am and pm)

Facilitated by **Rosie Tucker**, Community Facilitator at St Michael's Hospice, **Sarah Browning**, Frailty Nurse Practitioner – Better Together Frailty Service and **Jane Marquesen**, Community Educator, St Michael's Hospice.

These workshops offered the opportunity to reflect on your experiences and have conversations about, planning care for the future, the support available and the expectations versus reality.

**20 carers attended these workshops and 10 carer evaluations were received**

*"Very thought provoking and interesting to hear other carer's stories"*

## E. Your rights around carers assessments (am)



Facilitated by **Allyson King**, Project Manager Carers – East Sussex County Council and **Ami Cane**, Resource Officer Integrated Continuing Healthcare ASC.

This workshop offered the opportunity to share your experiences of Carer Assessments in East Sussex and learn about who can have an assessment, the assessment process and what may happen after an assessment.

**22 carers attended this workshop and 14 carer evaluations were received.**

*“Although the speakers were very good, they couldn’t always give the answers to the questions”*

## F. Your rights around benefits (am and pm)

Facilitated by **Oliver Mawdsley**, Outreach Manager, Department of Work and Pensions and **Michele Javary**, Macmillan East Sussex Welfare Benefits Advice.

These workshops offered the opportunity to share your experiences of accessing benefits in East Sussex and learn about your rights as a carer around, access to benefits and understanding Appointeeship.



**34 carers attended the workshops and 20 carer evaluations were received.**

*"Loved the interactive format"*

## G. Your rights around work and education (pm)

Facilitated by **Paul Turk**, Team Manager Ambitions & Brighter Futures Southdown, **Rosemary Millward**, Vocational Specialist.

This workshop offered the opportunity to discuss your experiences of work or education and learn more about your rights in the workplace as well as the local support available.

**10 carers attended this workshop and 10 evaluations were received.**

*"One of the best bits about the forum was Meeting Paul Turk from Ambitions who actually saw me on the day before the forum. He is excellent supporting people into employment"*

*"Excellent advice and ability to answer questions"*

*"I learnt so much about law and rights and funding for carers and funding courses"*

### Workshop for professionals - Carers Rights



For the first time at the Carers Forum a workshop was held specifically for professionals.

A morning session was offered around Carers Rights. This was facilitated by **Paul Turk**, Southdown Ambitions and **Carole Gregory**, Care for the Carers.

**28 professionals attended, and feedback was very positive.**

*"... Carers Rights workshop very informative and interactive."*

*"The professional workshop on 'Carers Rights' very informative and I learnt a lot"*

*"I found it fascinating to learn from the workshop 'Carers Rights' that there are a lot of people that don't consider themselves a carer even though they technically are one"*

*"Carers quiz was an eye opener. Good to get figures"*

## Film Premiere (13.15 pm – 13.35 pm)

As part of Care for the Carers writer in residence initiative “Carers’ Words, Carers’ Lives” five short films have recently been produced complimented by a trifold pamphlet highlighting key messages from the films. Three of those films were premiered at the autumn Carers Forum, introduced by Evlynn Sharp, Writer in Residence.



They can be viewed on YouTube along with the film premiered at the previous forum and three other short clips where carers, Chris, Derrick and Roger, talk about getting a break from their caring role <https://www.youtube.com/channel/UCkaUvQQCBGHmfW0Xm5NBxtA/videos>

We would like to thank Evlynn, Dan Bridge the film maker and carers Janice, Ian, John, Charlotte and Jason for sharing their experiences through these wonderful films.

*“Carers stories are powerful and help connect us all to the reality of caring - more of these films please! Inspired to tell our story now”*

A number of attendees identified the films as the best bit about the day and 40 of 43 carers that rated the films marked them good or excellent.



*“Watching the films, so moving and powerful and a medium for carers to share their experiences”*

*“Carers’ Words, Carers’ Lives books and film”*

*“Hearing carers personal experiences and stories and getting feedback on our services”*

*“Beautiful films!”*

## What Carers Said – themes from workshops

*“Don't tell us how not to get services - tell us how to get them please! We don't want to know what you can't do for us, we want to know what you can do for us!” (Carer)*

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 some of the key themes that emerged, linked when possible to workshops delivered throughout the day.

**PLEASE NOTE:** Full workshop notes are available as part of a data pack which also includes depersonalised data from evaluation forms (carers and professionals).

A common factor across all of the themes covered at this Carers Forum was that carers' experiences varied significantly depending on the individual practitioners they met and who dealt with their case. This applied equally across health and social care, in hospital or community settings.

### A. Your rights when the person you care for is admitted to hospital

- **Communication was a key theme in this workshop** with carers saying that this needs to be improved between patients, carers and medical staff, NHS providers and benefits agencies, between hospital departments, care homes and respite provision.
- Particular concerns were raised about communication when the cared for person is living with dementia and around **how much warning carers are given when the person they care for is going to be discharged** with as little as three hours' notice given as an example.
- While understanding the reasons for **electronic communication** many carers still value getting information on paper.
- Carers highlighted that **Lasting Power of Attorney** is at times being ignored.
- It was expressed that the **system can sometimes still be very slow** when things are changing for the carer and cared for person very quickly.

### B. Your rights when you are a mental health carer

- Carers felt there is **no clear pathway to relevant helpful information**. They felt there is a lot of information available, but it is difficult to sift through.
- **Carers often don't feel listened to** - the cared for person's right to privacy and confidentiality versus the right of the carer to discuss care planning is a barrier with staff focused on the cared for person. Tensions arise if the cared for person disagrees with carer or doctors around diagnosis/treatment.
- **A Carer's relationship with the person they care for is often complex**. Feelings carry on when the person being cared for dies but services stop.
- Carers feel there is **disparity of care across East Sussex** as services are not fully rolled out and there is often inconsistency in team communications. **Access to services** can vary depending on the GP and there can be a long wait for help. Carers expressed it is

still down to luck, depending on the GP, as to the quality of care, including what medication someone receives.

- **Carers' needs vary** and a network of support is required. Carers identified the importance of independent support groups which are outside NHS. They wanted more concrete information on the way forward with support/peer groups, some want a formal complaints procedure to NHS.
- **Carers raised questions about using the third sector (charities)** to provide complimentary support. With the focus on using limited resources to address extreme and complex needs it was felt that often patients and carers are not eligible for NHS services and get referred on to charitable agencies. Carers asked questions about the training and competence of staff and volunteers.
- **Practical issues are automatically dealt** with but there is often emotional distancing from the cared for person, while dealing with services, etc.

### C. Your rights as a carer around community based health care

- It was expressed that carers should be able to access **flexible arrangements for making GP appointments**, specifically being able to make appointments by email.
- Concerns were raised that there is an **assumption that if your partner has dementia then you (the carer)** are well taken care of which isn't everyone's experience.
- Some carers felt that **professionals don't look at what assessments** have been done before or share information.
- Carers spoke about how they were not trained carers but were expected to undertake care and medical tasks.

*"I have hoisted the cared for person for 30 years. The care agency asked if I am trained. I said no but have done it for all those years. They said I needed training and a certificate and if not, I could not help the paid carer. But if I didn't help the carer they wouldn't provide someone who could help!" (Carer)*

- Carers also talked of when Community health care support is removed and the impact this has.

*"If they decide that you are no longer eligible, the services are removed quickly and then you have to go through an appeal system that can take months and, in the meantime, you still have to care for him with no care services" (Carer)*

*"Community health care has been taken away. The cared for person is 33 years old and cannot communicate and have complex physical and mental health needs." (Carer)*

### Carers' Health and Wellbeing (cross cutting issue for workshops A, B and C)

- **Delays in responding to a carer's requests for help, complaints or questions** as well as last minute decisions around discharge or changes to care plans have a significant impact on a carer's health and wellbeing, including stress levels.

- This is **particularly damaging when carers are managing their own mental or physical health conditions** as well as those of the person they care for. **Trying to negotiate the system** at these times is particularly challenging.

#### D. Your rights when end of life conversations are approaching

- Carers expressed how they experience significant **regret and guilt at this time**, with high expectations of what they should be able to deliver even when they understand the reasons why this is not possible.

*“Carers are doing the best they can at a difficult time, so need not feel guilty about the life decisions they make” (Facilitator)*

- Carers that started **planning, putting things in place or discussing end of life wishes in advance** expressed how they could really see the benefits but this can be a very difficult process.

*“I know what she wants and that helps. My sister-in-law wasn’t prepared when her husband was dying – it was so much harder for her” (Carer)*

- The challenges faced when **the cared for person is reluctant to talk about things like Advance Care Planning and the sensitivity needed when discussing ‘Do Not Resuscitate’** were explored and it was recognised the important part a health/care professional can play when they know the person well and can support the carer at this time.
- A carer raised issues around legislation, moral and ethical dilemmas that prevent a cared for person’s life being ended prematurely when their quality of life has deteriorated significantly.

#### E. Your rights around Carers Assessments and Adult Social Care

- Concerns were raised around the **quality and consistency of Carers Assessments** being undertaken.
- Carers were very aware of the **pressures that Adult Social Care is under** mentioning the impact of government cuts and recognising that many carers asking for help from the system which is under pressure and struggling to deliver the support.
- Carers spoke of how accessing respite is a continuing issue with difficulty knowing how to obtain it and who is eligible.

#### F. Your rights around benefits, financial and legal issues

- Overall, carers feel that the benefits system is very complicated and **not fair for many carers**.

*“It’s **unfair that as carers’ we can’t retire** – everyone gets a State Pension, but we cannot get Carers Allowance on top of that” (Carer)*

- Carers also expressed that there is **not enough information given to carers** about what benefits they can claim and that more support should be available to make the right legal and financial decisions.

*“Carers should be able to access **free legal advice** about applying for Lasting Power of Attorney and **free financial advice** to review their whole financial situation and plans for the future in relation to their finances” (Carer)*

- While some carers were positive about **the online carers allowance form** others are still concerned about the trend towards all information and applications being online (even when there is reassurance given that other options are still available).
- It was suggested that there could be a **fast-track Carers Allowance process** for carers of those who are terminally ill (it normally takes about 8 weeks to process).

## **G. Your rights around work and education**

- Often **carers won't say they are caring** because they think they won't get a job. Many carers have to **give up their jobs to be a full-time carer**.

*“I had to give up my career to care for my daughter, I had a high-powered job, and cannot go back as I have been out of work too long – 17 years. My options are narrowed. I don't want to volunteer or talk about caring – burnt out. Hard choices to make, myself or cared for. People have no understanding unless they have experienced it” (Carer)*

## Hints and tips for carers (from workshop facilitators and carers)

### Hospital Services

- **Welcome leaflets** that describe staff on the ward and what they do should be given to patients/carers on admission now.
- **The patient pack** was launched six months ago, and hospital discharge procedure is highlighted in there - staff try to plan discharge on admission.
- Ward staff will always need to see the original **Lasting Power of Attorney** - they should always ask so it is worth being prepared.
- **Risk assessments** have to take place when the cared for person is admitted from home to hospital and then is returning home and this can take some time.
- Patients should be **copied into any communication** exchanged across consultants/hospital staff (emails or letters).
- **The Patient Passport** is a user-friendly form that informs the hospital about the new patient. It provides simple information to all hospital staff, so they can recognise barriers. This is a national service.
- There are very few restrictions on wards regarding what we can and can't do around when visiting. For example, **it is always worth asking if you would like to stay with the patient longer.**
- **Have an overnight bag ready** in case of hospital admission (washbag, medication, slippers, night and day clothes - not towels, they will get lost); there is a medication passport that can be used.

### Mental Health

- **An Advance Statement or Lasting Power of Attorney for health** is very helpful. Some carers agree with the cared for person in advance that they can share information even if the cared for person later disputes this. This opens the door to engagement even if the cared for person is suspicious /the carer is not trusted. It also provides an opportunity to say what care and support you would like in the future.
- Carers need to know enough to help whilst respecting a cared for person's right to confidentiality. ***"Be firm and clear – put things in writing" (Carer)***
- **As a family or friend carer you have the following rights regarding information sharing:**
  - Know what information we can share with you and to understand when information can't be shared.
  - Know who to contact, usually this will be the Lead Practitioner of the person receiving care from our services. The Lead Practitioner helps the person and family and friend carers access the help they need.
  - Talk to someone about your concerns, especially to avoid crises and when there are different views.
  - Discuss an issue that you already know about. We may ask you questions to determine your knowledge about the specific topic before we can give certain information.

- Be involved in care and risk plans, unless there are clear reasons why this is not possible.
- Be given general information about mental health problems, types of interventions and medication and local services
- Your information will be treated as confidential and not be shared with your loved one without talking with you.

## Carers Allowance

- **There are paper based and telephone versions of the Carers Allowance form as well as the online version.** The Department of Work and Pensions (DWP) has a free service (Visiting Officer) for people who are vulnerable to **visit at home** to complete the form. By the end of the year all DWP numbers will be Freephone.

*“I applied for Carers Allowance and it was very straightforward and easy – I did it online and it didn’t take long at all” (Carer)*

- DWP facilitator advised **that ways of prioritising applications are being considered** and suggests that any carers looking after someone under special rules should telephone Carers Allowance to ask for their claim to be fast tracked under special rules procedures which will mean the claim will be looked at urgently.

*“When having an assessment, consider your very worst difficult day and focus on needs for that time. The situation usually gets worse and you have to think of the future times” (Carer)*

## End of Life

- It is so important to **have the conversations about death and dying as early as possible** – before there is a crisis.
- The **Age UK film and booklets about Advance Care Planning ‘Let’s Talk about Death & Dying’** and **Care for the Carers After Caring booklet** are useful resources.
- If the cared for person is reluctant to talk about Advanced Care Planning **it can sometimes be easier to discuss this with an outsider**. Possibly ask the District Nurse or paid carers to try to initiate discussions. Tools are available to help initiate conversations – The Conversation Game, Grave Talk.
- **It is recommended that anyone near 50 (or younger) should talk and think about Advanced Care Planning.** This is usually driven by Healthcare Professionals but carers and cared for people can write one independently. This can be empowering for carers and the cared for person as it gives some control in a situation where a lot of things are not in your control.
- It is a very good idea to **set up a Lasting Power of Attorney in advance** giving decision making and power to someone you trust.

**PLEASE NOTE:** The autumn/winter 2017 CareLine magazine includes articles on Universal Credit and advice for working carers while the winter/spring 2018 edition includes articles on the rights of carers around hospital discharge, mental health services and benefits.

## Next Steps

*“I have attended lots of these forums and I hear the same stories time and time again. You take notes and take them back, what actually changes? Good intentions but are they listened to?” (Carer)*

This quote reflects what carers often feel, that what they say is not listened to and that nothing changes as a result of consultations, surveys or focus groups to which they are invited to contribute.

After such a vibrant event, with carers sharing openly their experiences and professionals giving their time and expressing their commitment to change, it is essential that there are some tangible outcomes to report over the coming months.

At the next Carers Forum, in the spring of 2018, Care for the Carers want to ensure that we can evidence the impact this work is having on the experience of unpaid carers in East Sussex and what has changed as a result of this event.

Already many workshop facilitators have fed back how valuable the day was for them:

*“I was so pleased to have taken part in the Carers Forum. The workshop discussions were stimulating and uncomfortable at times, but good to be challenged with the realities” (Sussex Partnership NHS Trust)*

Others have already started initiating change as a result of what they heard from carers and other facilitators:

*“We have had a success on the back of your event, where Michelle (co facilitator) raised the issue that the digital claim form does not allow you to print additional information. I took this back to our digital team who have now allowed this page to be printed.” (DWP)*

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 carers rights, 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.

- 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 autumn Carers Forum, have access to information around their rights 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 openly 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.

- Through membership of the new Collaborative Stakeholder Group, Care for the Carers will ensure that carers' needs and experiences are embedded in decision making processes.
- A full data pack, made up of depersonalised 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.
- Carer for the Carers will offer carer awareness/carers friendly community training, and action planning support, across health, social care and third sector provision.
- Learning from this forum will inform planning around content and delivery of the next Carers Forum, spring 2018.

## Appendix: Carer Friendly Communities



Over the last two years Care for the Carers has been working with local businesses and service providers to support them to become more carer friendly, **doing small things that can make a big difference to an unpaid carer's life.**

We now have a network of carer friendly services, most of whom have identified **Carer Ambassadors, Leads or Champions** who have **attended Carer Awareness training. These contacts have** signed up to be the **'go to person'** for colleagues and service users who are carers themselves or who want information for someone they know.

At the autumn 2017 Carers Forum, Care for the Carers recognised some of these organisations who are listening to carers, learning more about their needs and adapting their services to be more carer friendly.

### Southdown Ambitions Service (Accepted by Paul Turk)

Ambitions offers free vocational support to carers. They are always the first to offer to work in partnership with other services for carers and join up to deliver campaigns, carer awareness and engagement activities.

### Age UK East Sussex Community Navigator Service and Information and Advice Service (Accepted by Christine Ketley)

The Information and Advice Service provide free and confidential advice for older people, their families and friends and professionals who may be helping to care for older people. Recently working in partnership with Care for the Carers through a shop front venue in Hastings.

Community Navigators work in conjunction with GP surgeries providing non-medical support and advice to older people and their carers.

Paid staff and volunteers from both these services have attended carer awareness training, work closely with Care for the Carers and identify and support carers on a daily basis.

### East Sussex Healthcare NHS Trust Frailty Practitioner Team (Accepted by Sue Lyne and Team the Frailty Practitioner Team)

The Frailty Practitioner Team have initiated many practical changes to their working practice since participating in carer awareness training earlier this year. They have also actively encouraged other health providers to work towards being more carer friendly and work more closely with Care for the Carers.

**NHS Eastbourne, Hailsham and Seaford CCG and NHS Hastings and Rother CCG (Better Together) Engagement Team (Accepted by Josh Broadway)**

The Engagement Team have opened doors to enable us to raise awareness of unpaid carers with GPs and Patient Participation Groups and continue to support our work across the Better Together area.

**Sussex Partnership NHS Foundation Trust (Accepted by Bryan Goodenough, Governor).**

The Trust is working hard to improve carer experience by listening and learning to their needs and realities. They are working closely with carer organisations through their Carer Lead and Triangle of Care work.

**An increasing number of local organisations are working with Care for the Carers and are on the journey to become more Carer Friendly. At future events, and through the Careline magazine, we will continue to highlight their work and encourage others to join us in making East Sussex the most Carer Friendly County.**