

Summary Report

Carers Forum Spring 2017

Building a Carer Friendly Community

Thursday 11th May

King's Centre, Eastbourne



"It is important for carers to share experiences with professionals and other carers. Hopefully this will inform the decision making processes on which all carers really rely on".

Key Messages from Carers to Service Providers and Decision Makers

Overall carers said they wanted:

- **Health and social care professionals to recognise and respect the role of** carers and consult them over care plans. Carers want to be listened to not talked at.
- **Services to be coordinated**, including health, social care other statutory and voluntary services. Carers do not want to be passed from agency to agency and to tell the same story over and over. There should be **better information sharing between agencies** and ways to ensure that necessary information about the cared for person is shared with carers.
- Carers to receive **timely and appropriate support** from professionals, for example in OT home assessments.
- **Carers' rights to be respected** and supported, including their right to have time off, to combine work and caring if they choose, and to have the financial support they need to continue in their caring role. To enable this, funding for respite and frontline support must be maintained, and services should be available across East Sussex, not just the major centres.
- **Carers' well-being to be a priority**, and they should receive the support they need, particularly at times of transition, e.g. when they first become a carer, and when the person they care for has to go into residential care. Voluntary sector services that support carers directly should be maintained and expanded.
- **Being a Carer Friendly Community** to be mandatory. With experiences varying significantly some carers felt they were seen as **'difficult' or 'invisible'** and that **'red tape'** can get in the way of employers or businesses making the changes that are needed. They need to be more carer and disability aware.

Introduction

Care for the Carers is the Carers Centre for East Sussex, and provides services and support for unpaid carers across the county.

Each year we hold **two Carers Forums**, which explore issues that have been identified by local carers as important to them. **The forums are an opportunity for carers to share their views and experiences, learn about issues important to them and build on their own social network.**

The Forums are held in **different locations** across the county to encourage attendance from as wide a group of carers as possible and transport is provided for carers who wish to attend but would have difficulty reaching the venues without support.

Each forum has an **overall theme** and includes an **information marketplace** and **workshops** alongside opportunities to contribute to local research, consultations and other **engagement activities**. Carers value the chance to **socialise** over lunch and refreshment breaks, catching up with old friends, meeting new people and gaining peer support.

Workshops have been a popular addition to the forums over the last year. They are led by professionals, often with support from a local carer, and are designed to encourage carers to express their experiences, views and ideas. There is a **designated note taker** from Care for the Carers for each workshop, and these notes and overall event evaluations form the basis of this report.

Spring 2017 Carers Forum

This Carers Forum was held on 11th May 2017, at the Kings Centre, Eastbourne. The theme was '**Carer-Friendly Communities**'.

After a welcome and introduction by **Jennifer Twist**, CEO of Care for the Carers, Carer-Friendly Communities certificates were presented to nominated organisations including Carers Breaks and Engagement Team (ESCC, ASC) Locality Link Workers Team (ESCC), Proactive Care Practitioner Team (Better Together, East Sussex Health care NHS Trust) Respite and Community Support services Team (ESCC, ASC), HARC, Brighton and Hove Buses and Stage Coach.

A market place of 33 information stands were booked by a wide range of relevant local service providers many of whom were also seeking to hear carers' views of the services they provide or key issues relevant to carers needs.

These included: - Age UK East Sussex, Alzheimer's Society, Association of Carers, Brighton Carers Centre, Brighton and Hove Buses, Brighton & Sussex Medical School – Dementia Studies, Brighton & Sussex Medical School - Psychosis Research, British Red Cross, Coastal Wellbeing, East Sussex Families and Carers Team - Cranstoun, Disability Inclusion, Eastbourne Health Champions (SCDA), East Sussex Against Scams Partnership, East Sussex Better Together Public Reference Forum, East Sussex Fire and Rescue Service, ESCC Adult Social Care – 1Space, Hastings Advice & Representation Centre (HARC), Health in Mind, Ice

Pro – Improving Carers Experience Programme, Macmillan, Motor Neurone Disease Association, NHS Hastings and Rother CCG, Parkinson's UK, Safeguarding Development Team, Southdown Ambitions, St Michaels Hospice, St Wilfrid's Hospice, Sussex Community Development Association (SCDA), Sussex Downs College and University of Sussex.

Care for the Carers also had information stands encouraging carers to contribute to a Carer Friendly Community survey and promoting services and opportunities available across the county.

At lunchtime, there was a special opportunity to see the new Care for the Carers film, ***Carers' Words, Carers' Lives***, and watch a performance of poetry written by carers. The film featured Cynthia, Josh, Meena and Peter who share their experiences of being a carer, and can be viewed on the Care for the Carers website: cftc.org.uk/2017/03/30/carers-words-carers-lives/.

The film is part of an ongoing project with our writer-in-residence, Evlynn Sharp, who also gave a unique performance of poems by carers who have taken part in creative writing workshops with her, and whose lives are shaped in part by their caring roles. These poems are taken from the book, ***'Carers' Words, Carers' Lives'***, published in 2017, which is available from Care for the Carers.

81 carers attended the forum and **10 cared for people** (in total 34 carers booked places but could not attend on the day) As well as the professionals who staffed the market place stands and the 14 who facilitated **workshops 14 other guests** and 3 volunteers were also in attendance.



Workshop Programme



At this Carers Forum we had 10 workshops on 7 different topics.

Making a carer friendly community – dementia carers. (AM & PM)

Examples of good practice and what could be improved in your local community in accessing shops, Banks, GP surgeries.

Facilitators: **Sally English** (Carers Breaks & Engagement Team, ASC)
Mandy Prior, Jayne Hicks & Allison Roberts (Carers Breaks & Engagement Team, ASC)

What makes a carer friendly community? (AM & PM)

What elements do you think make up a carer friendly community and what ideas do you have on how communities can become more carer-friendly?

Facilitators: **Carole Gregory** (CftC) - AM & **Grace Scrimgeour** (CftC)- PM

Making healthcare services more carer friendly. (AM & PM)

New developments in managing health and social care, how this works for carers, and what improvements are needed.

Facilitators: **Sarah Gorton & Min Stone**, (Locality Link Workers, ESCC)
Serene Russell, (PCP, Better Together, East Sussex Healthcare NHS Trust)

Making a carer friendly community - learning difficulties. (AM)

Best practice in respite care, and what makes a carer friendly community for carers of people with learning difficulties.

Facilitators: **Sue Booker** (Respite and Community Support Services, ESCC)
Teresa Flower (CftC)

Making a carer friendly community – autism. (AM)

What services are available for people with autism and their carers? Increasing autism awareness, and self-care for autism carers.

Facilitators: **Jane Caygill** (CftC) & **Meraud Davis** (Autism Sussex)

Funding for residential and day care. (PM)

Discussed the financial assessment process undertaken by Adult Social Care and key worries, including the legal authority to manage finances for the cared-for person.

Facilitators: **Teresa Andrews** (HARC) & **Amelia Osmond** (ESRC)

Making transport services more carer-friendly. (PM)

Examples of good practice from transport companies, and discussion on how we could make transport services more carer-friendly.

Facilitator: **Victoria Garcia** (Brighton & Hove buses)

There are always mixed reviews about the workshops as there are always carers that hoped for something different than they experienced. It is almost impossible for facilitators to meet the needs of all carers in the limited time available. However, the vast majority of feedback was positive and some of the comments are included below. **Carers said:**

Healthcare: *“Excellent workshop, looking forward to knowing more about the locality link workers really getting to grips liaising with GP’s”*

Learning Difficulties: *“It is important for carers to share experiences with professionals and other carers. Hopefully this will inform the decision making processes on which all Carers really rely on”.*

Autism: *“Autism awareness training is needed in hospitals, at least one person on each ward and special waiting rooms for people with autism”*

“Autism friendly sessions where carers don’t pay are valuable”.

Transport: *“Good workshop – Stagecoach in Eastbourne need to roll out Carers Card for transport discounts”. “Brilliant workshop, I have always found our stagecoach drivers excellent”.*

Funding: *“Great facilitators”. “Local Authority providers seem very George Orwell 1984 but I do understand the legal obligations”*

Dementia: *“Really good workshop – information sparked a light bulb moment”. “Not what I expected”. “It was all about Adult Social Care Funding”.*

Carer Friendly Communities: *“An inspiring workshop with positive points made by both the facilitator and participants”. “Obviously communication and assumptions are a big issue”.*

Key Themes from Workshops

Workshops at the Carers Forums give carers the opportunity to express their views and talk about their experiences, as well as gain some useful information from professionals. Full workshop feedback and evaluation data is available on request. The following cross cutting themes emerged.

Professionals' attitudes to carers

Carers identified that they really appreciated it when they were identified and recognised as a carer by their GP or supported in preparing for the future by a District Nurse or Social Worker. However, carers often felt ignored, taken for granted and disrespected by health and social care professionals, and that there was a lack of understanding and empathy for the complexity and difficulties of their lives. They expressed that their special knowledge of the person they care for is overlooked by professionals

"I want to be listened to- as a Carer I know the cared for person best."

While it was identified that carer awareness is improving in hospitals, carers felt it had not reached registrars and consultants. Carers said that hospitals expected them to perform medical procedures at home, and their availability as carers is assumed in discharge plans, even though they are frequently not consulted about these:

"I care for my mother, and I felt ignored by registrars and consultants when it came to discharge. There needs to be more training in dementia awareness for senior staff. They should take carers seriously, for example, the consultant doesn't want to hear carers' opinions."

Carers' lives are often made more difficult by the lack of support from professionals in preparing homes after hospital discharge, and by delays and inconsistencies in OT home assessments:

"The OT team... promised to come out, but still haven't been- it feels like a complete mess. We were referred to a clinic. My partner has MS and multiple problems and we asked for the OT to assess the house, but 6-7 weeks later it hasn't been done."

Carers also mentioned some issues with their GP surgeries. They identified there needs to be recognition from GPs that carers cannot always get to appointments and need flexibility. They appreciated it when they were identified and recognised as a carer by their GP, and when they were included in PPG meetings, although these vary in their attitude to carers:

"[It was good] being included in a PPG meeting and being told they had a board for caring (Park Practice)"

"I chaired a local access group and went to a PPG meeting – the chair said, 'we don't discuss caring here.' I continued to attend meetings but got the same reception, so I emailed the secretary and resigned from the meeting."

It was felt that GPs are not always effective at signposting carers to services; carers sometimes feel that they have to educate their GP about services:

"I need to know information to educate my GP- it should be the other way around. I will be contacting my GP to liaise with the PCP."

In addition to their relationships with individual professionals, carers mentioned the difficulties in accessing services and information due to what seemed like a lack of co-ordination.

Coordination of services and information

Carers felt there was often a lack of co-ordination of services, between health and social care, statutory and voluntary, and even mental and physical health services.

"Services are not connected- I hate having to explain the situation each time."

Confidentiality issues were also a concern. Many carers who look after people who lack competency find that services will still only communicate with the cared-for, even if the carer has Power of Attorney:

"Letters sent to the cared-for should also be sent to the carer if cared-for doesn't have the capacity to deal with them. It's difficult to have to justify yourself every time, even if you have Power of Attorney- could there be a reference or a password?"

Another theme was transition which can be a stressful and emotionally challenging time. These transitions include when they first become carers, when the person they care for goes into residential care and when they are bereaved. This is a time when support is needed and when it was received was very much appreciated.

"It can be a shock to become a Carer – your life is put into chaos."

"The social worker asked me what I need – I didn't know until she told me what was available."

"I had a superb social worker. She foresaw the needs. She could see I wouldn't cope long term. She was patient and understanding and looked ahead."

Services can be difficult to access if you live in more rural parts of East Sussex, as provision is patchy in some areas and public transport coverage can be a problem:

"We are quite isolated, and it's harder to make journeys. We need things to be local."

Support for Carers

Carers appreciated services that helped them as a carer, including Care for the Carers, Counselling, Carers Toolkit courses, pampering sessions, support groups, Ice project and respite care

"Care for the Carers have been very helpful – I wouldn't be here today except for you."

Carers also appreciate specialist support and information around the cared for person's condition which they recognised supported them in their caring role such as Alzheimer's Society.

Respite and day services are also important to carers, enabling them to have holidays or just some regular time off from their caring role, but can be expensive and of variable quality.

Carers Rights

The 2014 Care Act established in law some key rights for carers, including the right to ask for a Carers Assessment. However, some carers felt that this was ineffective in promoting their rights and there was a sense that they promised a lot but often delivered little:

“I had a Carers Assessment, but haven’t heard anything. There were lots of visits at the beginning but now it has all gone quiet”

Carers said they were not always informed about the different ways in which they could complete the Carer’s Assessment forms. While some people prefer to do the form on their own, some like support over the phone, while others want face to face support.

“I was sent forms to do a self-assessment. Then they phoned and said they would do a phone assessment. I had spent 2 hours doing the self-assessment!”

There was a lack of clarity on Carer’s Personal Budgets- eligibility criteria, what they could be used for, whether they were one-off or ongoing, the timeframe for decisions and process for challenging refusals.

“I had an assessment on the phone and was asked what I wanted to do. They funded my swimming, but I thought it was a one-off. I had about £120”

Tolerance, understanding, disability-friendly and carer-friendly businesses

Carers are also concerned about the reaction from the public and businesses to themselves and the person they care for. While some businesses and individuals have taken on board the ideas of carer and disability awareness, there is still need for greater understanding.

They frequently experienced intolerance from the public in public places and shops.

However, they appreciated both kindness from individuals and the initiatives from some businesses to meet the needs of particular groups, such as those with dementia or autism, and their carer. This ranged from special shopping sessions or till arrangements, to special screenings and events, and arrangements at venues that give carers free or cheap tickets. However, there was still much room for improvement:

“There needs to be greater awareness and education, e.g. in schools, to shine a light on carers and people with disabilities.”

“The bus driver was sympathetic and waited until we were seated to move off”

Building a Carer Friendly Community.

Alongside discussion in Carers forum workshops Carer Friendly Community Surveys were completed on the day and afterwards online and during Carers Week (June 2017).

Carers identified that community initiatives that recognise and support carers can make a big difference although few think that they are a reality at present. Some carers had good experiences with their employers, including being able to discuss their caring role with line

managers, and access to flexible work practices. However, the bigger picture is often less positive, with carers struggling to juggle work and their caring responsibilities.

Over one fifth of carers surveyed said that important services like banks, pharmacies and shops, identified them as a carer, with one quarter saying that local services and businesses were age, disability and carer friendly. 29% of carers in our survey knew about carer-friendly initiatives within businesses, including home delivery, flexible appointments or carer discounts. The bereavement departments at BT and DWP were mentioned as helpful.

“Shops in the local area are now advertising that they are dementia or autism friendly with staff who are trained to help their customers which raises very important awareness for the carer and the cared for person”.

“I live in East Sussex where a variety of very successful and popular care friendly support activities are in place”.

There were concerns raised however that some venues and services that claimed to have accessible facilities or be carer friendly aren't.

“Some venues claim to have accessible facilities e.g. loos, but often these are poorly planned spaces - cramped, one sided, up 3 steps etc.”

“Statutory education providers (schools and colleges) don't care about those students who are carers, they only care about the money they get if the student completes their course. Carers are just seen as 'difficult' students because they don't fit the norm”.

The Next Steps

- Information and findings from the forum workshops will be shared with commissioners of services for carers across the county:
- Reports will be publically available, electronically through the Care for the Carers website, and in printed form from Care for the Carers.
- What carers have shared around the challenges they face will inform the theme of the autumn Carers Forum 2017 and future engagement activity.

The Next Forum- Autumn 2017

Taking into account what carers feedback the next Carers Forum will be a round the theme of ***Carers' Rights, Carers' Experiences and will be held at Sussex Downs College in Lewes on Wednesday 25th October 2017.***

It is hoped that workshops will include the following.

- Your rights and experiences when the person you care for is **admitted to hospital**
- Your rights and experiences around **healthcare in the community**
- Your rights and experiences as a **mental health carer**
- Your rights and experiences when the person you care for is approaching **end of life**
- Your rights and experiences around **work and education**
- Your rights and experiences around **benefits** for carers
- Your rights and experiences around **Carers Assessments**

Acknowledgements

Care for the Carers would like to express our thanks to everyone who helped make the spring 2017 Carers Forum such a success. This includes all those involved in planning and delivering the workshops, people who organised and staffed the information marketplace stalls, and our colleagues at Care for the Carers who worked behind the scenes and around the venue to ensure that everything ran smoothly.

Most of all, we would like to thank all the carers who took the time to come to the forum, to participate in the workshops and to share their views, experiences and ideas openly and honestly. They are the reason we have the Carers Forum, and their enthusiastic participation is what makes it worthwhile.

"A very informative and interesting day"

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