



## Spring Carers Forum 2016

## Taboo Subjects

## Summary Report

*“Without a shadow of a doubt the best thing for me was the response from the carers which was overwhelmingly positive. I lost count of how many carers came up to me who were happy, cheerful and uplifted and that was in spite of the nature of some of the topics of the workshops. The fact that the organisers and speakers managed to achieve this for carers is just amazing. None of the topics were 'safe' topics so all were potentially very emotive and challenging”*

## Spring Carers Forum 2016 – Taboo Subjects Carers said ...

- *They wanted more information about care options (full time or respite), services that are available, how to make choices and the financial implications. They felt that the opportunity to talk about and understand these issues is essential*
- *They felt that opportunities to talk about end of life planning should be easily available for all but that this is not always the case. They were concerned carers lack of understanding around financial issues can impact on their decision making when it comes to difficult end of life conversations*
- *They felt their own mental health issues were not always recognised by professionals in the same way as the people they cared for. Caring for someone with mental health issues has an enormous impact on carers own health and wellbeing which should be acknowledged and addressed more equally*
- *They felt service providers rarely consider the impact that changes in relationships with the person they cared for had on their mental health. They saw counselling as valuable and felt evening and countywide groups, where carers could speak about feelings and experiences, would be good. A closed CftC Facebook page was also suggested*
- *They highlighted concerns around financial issues and asked for more information and support. There is a lack of understanding of benefits eligibility and concerns about costs in relation to respite/full time care and end of life decisions. There is also confusion about messages being heard around national legislation and the impact this will have financially on carers*
- *They wanted more opportunities to engage with their local MPs to ensure their voices were heard.*

# Spring Carers Forum 2016 - Summary Report

## Introduction

The spring Carers Forum 2016 was held on 4th May at the International Tennis Centre in Eastbourne and was attended by 126 carers and professionals from across the county.

Carers Forums take place twice a year and explore issues that unpaid carers have identified are important to them ensuring that carers voices are heard and influence decision making around issues that impact on carers lives. Difficult to talk about, or taboo subjects, was identified by local carers as an area they wanted to explore further.

The following workshops were held based on what carers had asked for:-

- **Mental Health** - Ice Pro offered two choices  
Am I a bit low or am I depressed?  
Suicide, self-harm and aggression,
- **Creative Care Options** - Think Local, Act Personal - East Sussex County Council
- **End of Life Conversations** - St Wilfrids Hospice, St Peter and St James Hospice and St Michaels Hospice
- **Relationships, intimacy and sexuality** - Sharon Blight Independent Counsellor

The key note speech was delivered by Laura Bennett from Carers Trust, offering a national perspective, and a busy marketplace of information and engagement opportunities.

**The planned outcomes for the day were that carers would have the opportunity to:-**

- share their views, experiences and needs.
- learn more about support available to them and feel more confident about accessing opportunities and support
- contribute constructive ideas about how services and support could be improved.

Alongside this further anticipated outcomes were around professionals becoming more carer aware, networking and strengthening of partnership working.

An evaluation report has been produced including full feedback on the event and carer's voices from the day. An article is included in the summer edition of Carline and the Carers Trust PowerPoint presentation and a short article is included on CFTC website. This will be followed by the summary report and accompanying slides.

## About the day

### Attendance

- 92 carers booked a place with 68 attending on the day (47 women and 21 men)
- Dementia and Alzheimer's carers were the most represented (11 booked, 4 attended on the day)
- Carers from across the county attended (but only 8 from Hastings and Rother)
- Most carers were over 50 years old (only 3 known to be younger)
- 58 professionals attended (not all at the same time) from a wide range of service provision from across the county.

## Evaluation feedback

41 carers filled in evaluations on the day as well as 38 staff/ professionals. Notes from workshops were taken and the opening Q and A session were recorded.

**What carers said** - Carers were very positive about the Forum Theme of Taboo Subjects, the choice of workshops, communication before the forum, organisation on the day, and the refreshments as can be seen in the chart below.

Please rate the following:-	poor	average	good	Excellent
Forum theme		1	21	17
Choice of workshops		4	19	18
Communication before the forum		3	19	16
Organisation on the day		5	17	19
Refreshments		2	10	21
Opening speeches	2	9	18	11
Accessibility of venue	2	5	18	3

Accessibility of the venue divided opinion slightly and there was a wider spread of responses in relation to the opening speeches. The majority of those that attended enjoyed the format, the countywide approach and the subject matters covered. Carer comments included:-

*"Overall a very informative and enjoyable day well worth attending."*

*"Excellent as always!"*

*"I would like to see more events like this, a wonderful day!!"*

*"Thanks for providing it for us carers!"*

Evaluation of workshops was also very positive although longer and the chance to attend more workshops was voiced.

Did the workshop meet your needs?	poor	average	good	Excellent
End of Life Conversations		1	6	10
Am I a bit low or am I depressed?	1	4	8	5
Creative Care Options	2	2	8	11
Suicide, Self-harm and aggression		1	2	4
Relationships, Sexuality and Intimacy			4	4

Where workshops were rated poor, carers spoken to on the day said it was not that the workshops were seen as poor quality but not quite what the carer expected or needed at that time.

**Many carers when asked about future forums said they wanted something very similar:-**

- Care choices – understanding the options, making the decision and financial implications
- Accessing the right support - finances, employment, information maze and support available
- More on hard to talk about subjects and support around these issues
- Life outside caring – social isolation, social networking, hobbies and pampering

### **Professional evaluation forms were also very positive:-**

- 100% thought the forum theme of 'Taboo Subjects' was good/excellent
- Promotion of Forum was rated good/excellent by 27 people and rated average by 3.
- Communication & Planning of the forum was rated good/excellent by 30 people and rated average by 2
- 100% thought the organisation of the day was good/excellent
- 100% rated their overall experience of the forum as good/excellent

Feedback from professionals included in the full report gave constructive ideas for further improving the day will be taken into account when planning future forums.

### **Key messages from Carers to service providers voiced on the day included:-**

- They wanted more information about care options (full time or respite), services that are available, how to make choices and the financial implications. They felt that the opportunity to talk about and understand these issues is essential
- They felt that opportunities to talk about end of life planning should be easily available for all but that this is not always the case. They were concerned carers lack of understanding around financial issues can impact on their decision making when it comes to difficult end of life conversations
- They felt their own mental health issues were not always recognised by professionals in the same way as the people they cared for. Caring for someone with mental health issues has an enormous impact on carers own health and wellbeing which should be acknowledged and addressed more equally
- They felt service providers rarely consider the impact that changes in relationships with the person they cared for had on their mental health. They saw counselling as valuable and felt evening and countywide groups, where carers could speak about feelings and experiences, would be good. A closed CftC Facebook page was also suggested
- They highlighted concerns around financial issues and asked for more information and support. There is a lack of understanding of benefits eligibility and concerns about costs in relation to respite/full time care and end of life decisions. There is also confusion about messages being heard around national legislation and the impact this will have financially on carers
- They wanted more opportunities to engage with their local MPs to ensure their voices were heard.

### **Key learning for future events**

- Start promotion early through word of mouth, carers groups and partner network meetings, and then through social media, posters and written word (evidence – early promotion this time worked well and was evaluated positively)
- Encourage partners to more actively promote the forum through their own newsletters, groups and networks (evidence only 2 of the carers that completed an evaluation form heard about the forum from partners)
- Run a county wide forum again focussing on issues that carers feel strongly about (evidence - positive carer and professional feedback)
- Look at a venue in Hastings area for next forum (evidence low attendance from that CCG area this time)

- Identify theme of forum, identify and brief facilitators early (evidence – aids promotion as we have seen this time and ensures the best facilitators and the possibility of new networks and partners - one identified facilitator was unavailable when contacted)
- Consider themes around financial issues and more of the hard to talk about subjects carers are asking for (evidence feedback from carers and professionals)
- Consider working with colleagues from Carers Breaks and other partners to offer a more comprehensive/clear respite offer (evidence – drop out of dementia carers high)
- Ensure venue is well signposted and if possible look at a venue that offers spaces on one level (evidence feedback from some participants)

### Next steps

- Report will be presented to July 2016 Carers Partnership Board
- Action plans will be implemented to take forward Key issues identified by carers around services and needs
- Forum attendees will be encouraged/supported to take part in further engagement opportunities
- This summary report and PowerPoint presentation will be posted on CftC website and promoted through CftC E-newsletter and social media.
- Workshop facilitators and Carers Trust will receive the forum report
- Outcomes will be shared widely and will be reported on at the autumn Carers Forum.
- Autumn Carers Forum will be planned taking into account lessons learnt from this forum /carer's needs and wants.