



Sussex Caring for Carers Conference

Thursday 15th June 2017

Chowen Lecture Theatre, Brighton and Sussex Medical School,
University of Sussex, Falmer, BN1 9PX

Registration opens at 9am

Throughout the day various carer organisations from across Sussex will be holding a marketplace in the main foyer. They will be on hand to discuss the services and support available to carers and their care recipients.

9.00	Registration Opens
9.30	Cassie Hazell Opening Remarks
9.45	Dr Stephanie Daley & Laura Gallaher (BSMS) Measuring Quality Of Life In Carers Of People With Dementia
10.15	Dr Carl Walker & Vanessa Stone De Guzman (Uni. Of Brighton) Being On Red Alert – Research With Parents Of Disabled Children
11.00	Coffee Break
11.30	Professor Helen Smith & Dr Christina Jones (BSMS) From Negative To Positive: The Development Of An Intervention For The Carers Of People With Psychosis
12.00	Rachel Clarke (Uni. Of Sussex) Working Carers Living Well With Dementia: Sustaining Wellbeing Through Work-Life Reconciliation
12.30	Lunch
13.30	Rachel Starkings (Uni. Of Sussex) The PROACT Study: The Process Of Developing A Questionnaire To Measure The Impact Of Cancer On Carers
14.15	Anna Savage (Uni. Of Brighton) Visual Approaches To Knowledge Exchange As A Carer And Researcher
15.00	Coffee Break
15.30	Jill Scholl (Carer) My Experiences Of Being A Carer Involved In Research
16.00	Jacqueline Clarke-Mapp (Sussex Partnership NHS Foundation Trust) Friends And Family Carers Influencing NHS Services
16.30	Closing Remarks and Reflections
17.00	Closing of the Conference

Conference Abstracts

Below each presenter has provide a brief summary of their presentation, and details of how you can contact them if you would like more information.

Dr Stephanie Daley & Laura Gallaher

Measuring Quality of Life in Carers of People with Dementia

The C-DEMQOL study is funded by the Alzheimer's Society, and its main objective is to develop a condition specific questionnaire of quality of life for carers of people with dementia. This has involved interviewing a range of carers in order to identify the factors which influence quality of life for this group of carers. We have been field-testing the new questionnaire with carers in Sussex and North London, and will be looking for more carers to be involved in the field-testing later this year. For more information, please contact Laura Gallaher (l.gallaher@bsms.ac.uk) or 01273 873206

Dr Carl Walker & Vanessa Stone De Guzman (Uni. Of Brighton)

Being On Red Alert – Research With Parents Of Disabled Children

This talk will explore research with parents of disabled children – specifically, how researchers have interpreted the lives of parent-carers through different lenses over the last fifty years or so, and consider whether it is time to move things on. The researchers will report on a number of studies they have completed for Brighton-based disabled children's charity Amaze. These projects used multiple approaches, including in-depth interviews and film-making, to help parents not only describe their experiences but also to communicate them to people like clinicians and therapists. Through these empirical projects we explore the crucial care work of parent-carer led voluntary sector organisations and peer-support groups in the city. For more information, please contact either Dr Carl Walker (C.J.Walker@brighton.ac.uk) or Vanessa Stone De Guzman (V.StoneDeGuzman@brighton.ac.uk).

Professor Helen Smith & Dr Christina Jones (BSMS)

From Negative To Positive: The Development Of An Intervention For The Carers Of People With Psychosis

Carers of people with psychosis are themselves at an increased risk of developing mental and physical health difficulties. It is important that carers receive support that can fit around their caring responsibilities to reduce this risk. This programme of research has explored whether writing therapies are both helpful and accessible for carers of people with psychosis. This research began by looking at the effect of a writing therapy called Written Emotional Disclosure – which asks people to write about a past trauma or distressing experience. In light of our own learning, and that of the wider research community, we have since began a research study exploring the effects of a different writing therapy called Positive Written Disclosure – which encourages people to write about positive life experiences. This talk will describe our research journey, how carers have shaped this journey, and our present research study. For more information, please contact Cassie Hazell (C.Hazell@bsms.ac.uk).

Rachel Clarke (Supervised by Professor Jenny Rusted and Dr Lisa Chen) (Uni. Or Sussex)

Working carers living well with dementia: Sustaining wellbeing through work-life reconciliation

This study is looking at how wellbeing is sustained through the reconciliation of work and life. It is linked to the national Living Well with Dementia (IDEAL) study and is funded by the Economic and Social Research Council (ESRC). Using structured and semi-structured interviews, this research study aims to understand how working dementia carers achieve the balance between work and care. The main focus of this presentation, will be on the specific artefacts selected by carers to represent the work and life balance. For more information, please contact Rachel Clarke (rc362@sussex.ac.uk)

Rachel Starkings (Uni. Of Sussex)

The PROACT study: The process of developing a questionnaire to measure the impact of cancer on carers

This research is part of the Sussex Health Outcomes Research & Education in Cancer (SHORE-C) department. The aim of this study is to develop two scales; one measuring patient quality of survival and one measuring impact for informal caregivers. Both scales aim to measure the broader life impacts of cancer and cancer treatment such as impact on roles and responsibilities, in employment and within the family. For more information, please contact Rachel Starkings (R.M.L.Starkings@sussex.ac.uk)

Anna Savage

Visual approaches to Knowledge Exchange as a Carer and Researcher

Anna is currently studying for her PhD. She has completed a number of research studies that combine art and her role as a carer. Her research project "From Love's Stable Bow" started with the question "How can we use the process of animation and storytelling to support a sense of belonging within a community with a group of parents who have children with learning disabilities?" From the project, she produced a series of short films made by participants including her own film "The Boy Who was Different" <http://www.anna-savage.com/fromlovesstablebow/>. In her film "Handle with Care" she experimented with combining film extracts, animation and spoken word poetry to tell a little of my story and hopefully give an insight into the wonderful, challenging and frequently joyous world of caring for a disabled child and being part of a family. <http://www.anna-savage.com/handle-with-care/>

Jill Scholl (Carer)

My experiences of being a carer involved in research

Jill has taken part in various research studies and will share her perspective of this experience to the Carers Conference. Jill's oldest son has schizophrenia, the same illness that her mother struggled with, and she also has the EPA for her stepmother who has dementia. She has used her lived experiences to help to train healthcare and social work professionals, and has a particular interest in early intervention, family inclusion and support. She has an interest in co-production; and appreciates the value of research. Jill is passionate about ensuring more studies are selected by carers and their loved ones. She will give an honest account of her experiences of being involved in research – the good, the bad, and the ugly.

Jacqueline Clarke-Mapp (Sussex Partnership NHS Foundation Trust)

Friends and family carers influencing NHS services

Jacqueline is a carer herself, and also works as the carer lead for Sussex Partnership NHS Foundation Trust. She will discuss the tools and support currently available to carers



via the NHS, and what the future holds. For more information, please contact Jacqueline Clarke-Mapp (Jacqueline.Clarke-Mapp@sussexpartnership.nhs.uk)



Marketplace Stallholders

Below are the names and contact details of the various organisations that you can meet at the conference marketplace. The marketplace will be held in the main foyer.

Changes Ahead

Changes Ahead is an organisation funded by Brighton and Hove council that supports carers of those with mental health issues. This service offers both individual and/or group support including, practical advice, social events and an advocacy service.

Address: The Vallance Community Centre, Unit 2, Conway Court, Sackville Road, Hove, BN3 3WR

Phone: 07935 302838

Email: changesaheadoakleaf@gmail.com

Facebook: Changes Ahead

Improving Carers' Experience Project (ICE Project)

The 'Improving Carers Experience' project produces information that will be relevant and useful to carers of people who have mental health problems. The project runs information courses for carers, has developed a booklet and a website and other activities, including offering training to mental health staff on carers' needs.

Phone: 01273 617100

Email: alan.icepro@btconnect.com or jane.icepro@btconnect.com

Sussex Partnership NHS Foundation Trust

SPFT provide NHS care across Sussex for people with mental health problems and learning disabilities. They also provide a range of specialist services across south east England. We care for people all of ages, from children and young people through to older people with conditions such as dementia.

Phone: 0300 304 0100

Email: info@sussexpartnership.nhs.uk

Website: www.sussexpartnership.nhs.uk/advice-and-support-carers

Carers Centre for Brighton and Hove

The Carers Centre offers different kinds of services working with and supporting young and adult carers in the city. Their aim is to improve the quality of life for carers in Brighton & Hove.

Address: 18 Bedford Place, Brighton, BN1 2PT

Phone: 01273 746222

Email: info@thecarerscentre.org

Website: www.thecarerscentre.org/

Engage and Create

Engage and Create is a social enterprise dedicated to transforming quality of life for people living with dementia and those that care for them. They offer training, resources and support through creative mediums.

Email: rachel@engageandcreate.com

Website: www.engageandcreate.com/

Facebook: Engage and Create

Twitter: @engageandcreate

Association of Carers

The Association of Carers provides free, volunteer-led support services to unpaid Carers in East Sussex.

Address: Association of Carers, Jackson Hall, Portland Place, Hastings, East Sussex, TN34 1QN

Phone: 0300 330 9498

Email: info@associationofcarers.org.uk

Website: www.associationofcarers.org.uk/

Sussex Armed Forces Network

The Sussex Armed Forces Network (SAFN) is a multi-organisational group from across Sussex which aims to improve the lives of the armed forces community. They offer support and training for carer's and families from the armed and ex armed forces community.

Address: Sussex Armed Forces Network, 36-38 Friars Walk, Lewes, East Sussex, BN7 2PB

Phone: 01273 403693

Website: www.sussexarmedforcesnetwork.nhs.uk/

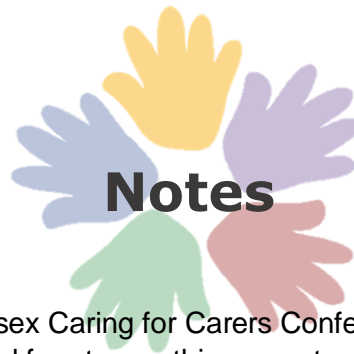
Ambitions

Ambitions are part of Southdown and offer free vocational support for carers – including employment, training and education support. The project is funded by East Sussex County Council

Phone: 01273 405822

Email: ambitions@southdownhousing.org

Website: www.southdownhousing.org/ambitions



We hope that you find the Sussex Caring for Carers Conference enjoyable and interesting.
Please feel free to use this space to make notes.