

# Realising that 'there is hope...' Supporting PEACE carers during the Pandemic and beyond

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7<sup>th</sup> September 2022

# Background

In the PEACE Pathway over the past three years, we have published three papers about carers, and one book chapter:

- ‘Carers’ views on autism and eating disorders comorbidity: qualitative study’ (2020)
- ‘A peer interview qualitative study exploring support for carers of people with comorbid autism and eating disorders.’ (2021)

The findings: the carers experienced high levels of unmet needs, a perceived lack of support from existing services, and subsequent feelings of isolation and frustration

# Background

- What also emerged was that the carers might benefit from support designed specifically for carers of people with autism and eating disorders. To date there had been a lack of support and resources for them, both online and face to face.
- Through our research this year we have found that this is also true of family carers of adult children with autism and other comorbidities.
- The carers interviewed in the peer-led 2021 study said that they would be interested in receiving peer-led support, specifically tailored to their needs.

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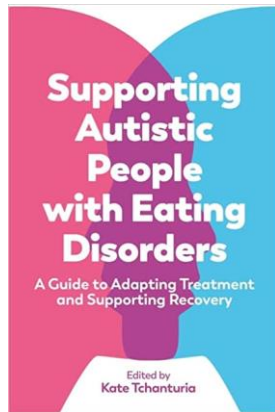
# First online peer-led support group for carers of people with autism and eating disorders

*held during first year of the Pandemic*

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## **‘Online PEACE coffee groups for families with autism and eating disorders during the Covid-19 pandemic’ (2021)**

This paper uncovered the social isolation felt by the PEACE carers and also the value for them of joining a peer-led group and connecting with other carers in the same situation, and not feeling alone. The carers said that they needed support like this on a permanent basis.



**‘Making the ‘Mental Transition’ from Clinician to Carer’, in ‘Supporting Autistic People with Eating Disorders’ (2021).** This chapter described how being a carer as well as a clinician means that I bring a dual perspective to researching carers’ needs; I can bring both clinical insights and my own lived experience as a family carer.

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## During this past year, we have..

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- Run a second online coffee group for PEACE carers
- Run online workshops tailored for PEACE carers
- Explored the experiences of other types of carers – by interviewing people who are looking after family members with autism who also have other mental health problems
- Reviewed existing online resources for carers of family members with autism and other mental health problems. This review confirmed that the PEACE coffee group paper (2021) is so far the **only** online intervention for carers of people with autism and eating disorders which has been evaluated to date.

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## The second online coffee group was open to PEACE carers from SlaM & St.Georges's

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- The carers really valued having a safe space to discuss their experiences with other carers in the same situation.
- The coffee groups were a space for carers to get support from the group leader and from each other. The focus is on the carers, not the people they are caring for.
- As with the first coffee group, these carers made connections with each other which lasted beyond the coffee groups themselves
- Carers said that the coffee groups made them realise 'that there is hope..'

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# Our findings from both PEACE coffee groups...

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- Carers value **online support**
- Carers value **connecting** with each other and hearing stories from other carers in similar situations
- Carers appreciate **peer support**. They get shared insights and advice from the lived experiences of others in the same situation
- Carers make real-life **friendships** from online support groups which can give meaning and hope to their lives
- ‘The peer support has made me feel better about being a carer’
- At the end of the second coffee group, this group of carers said that they felt more **optimistic and hopeful**

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# PEACE Pathway psychoeducational carers' workshops

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## Weekly Topics:

### **Week 1: 'When to support and when to step back?'**

Focused on Expressed Emotion; in particular – how not to be emotionally overinvolved. Emotional overinvolvement can create resentment.

### **Week 2: 'How do we know when our loved ones lack the capacity to care for themselves?'**

Ideas from *Expressed Emotion (EE)* & my clinical & lived experience

### **Week 3: 'De-escalating conflicts with loved ones'**

Focused on *Non-violent Resistance (NVR)* techniques – helping parents to 'cool things down'

### **Week 4: 'The importance of support networks and self-care for carers'**

Ideas from NVR & my clinical & lived experience

Feedback from carers about these workshops was very positive...



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## Feedback from carers who attended the peer-led PEACE workshops:

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- ‘very relatable; practical ideas; helped me think about my own interactions with my loved one; the workshops were tailored to the issues facing long term carers’
- ‘It was helpful getting insights from a carer rather than from a professional angle; you can take off your armour; it made me recognise the value and knowledge of carers’
- ‘Helpful ideas about how to help our situation’
- ‘Non-judgemental space’
- ‘Helps me feel more able to cope’ and ‘reinforces my confidence’

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# Findings from the PEACE coffee groups and workshops..

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## Areas that carers need help with:

### **Carer self-care**

Many carers are very far off caring for themselves because of the intense business of caring for their loved ones and the complex conditions they have.

### **How can carers focus on themselves?**

Many carers have several children with needs to care for, so when it comes to their own needs, have absolutely no energy left.

### **Self care can be the hardest thing to do**

Carers can feel 'programmed' to care for their loved ones and find it easy to neglect their own needs.

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# Carers appreciated the **flexibility and autonomy** that online support gives them

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Among the feedback we received about our interventions was:

- ‘Online is better because you don’t have to worry about getting somewhere.’
- ‘I wouldn’t be able to attend if it was face-to-face’
- ‘We can see each other on here but you can blank the screen if you don’t want to look at anyone or you don’t want someone to look at you.’

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## Other findings from the coffee groups and workshops

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- Carers may need a 'reset'
- Becoming a carer can be a traumatising experience, which is ongoing. How can we reset our lives to take our own needs into account?
- How can we focus on improved mental health, wellbeing and resilience for ourselves as carers?
- How can we retain hope, dreams and visions for the future?
- At the same time as trying to focus on their own needs, carers may be responsible for their loved one(s) on a daily basis, or 24/7.

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# Incorporating self-care when you have caring responsibilities for others

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## Strategies can start with:

Doing breathing exercises to focus on yourself and your own needs – micro self-care.

Being ruthless about cutting out other ‘responsibilities’.

Deciding what’s **essential** for your loved one’s wellbeing and your own wellbeing, and what is not.

Carers sometimes need ‘permission’ to focus on their own needs, and may need encouragement and support to do this.

Making sure you have your own ‘oxygen mask’ on before attending to others.

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# Creativity & carers' own physical and mental wellbeing

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- As a carer, your whole life may be based around caring for your loved one and maybe for others too.
- Creative activities involving art, play, music and movement can add a unique dimension to our lives.
- Taking the time to attend to one's own health needs and appointments is crucial to avoiding burnout.
- Getting emotional support from therapy or support groups for carers.
- All of these are dependent on carers having the time and resources to make these happen. I say to carers and to myself - Do think about yourself. Don't care for your loved one(s) and neglect yourself.

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## PEACE Pathway plans for carers' support over the next year; we are...

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- Launching a monthly online coffee group for larger numbers of PEACE carers
- Launching a monthly online coffee group for family carers of people with autism and psychosis
- Running more online workshops which are specifically tailored for carers of family members with autism and other concurrent mental health problems
- We will evaluate these activities and let you know about the findings next year.

Thank you!

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