PEACE
Pathway for Eating disorders and Autism developed from Clinical Experience

How the PEACE Pathway has supported carers in the Pandemic

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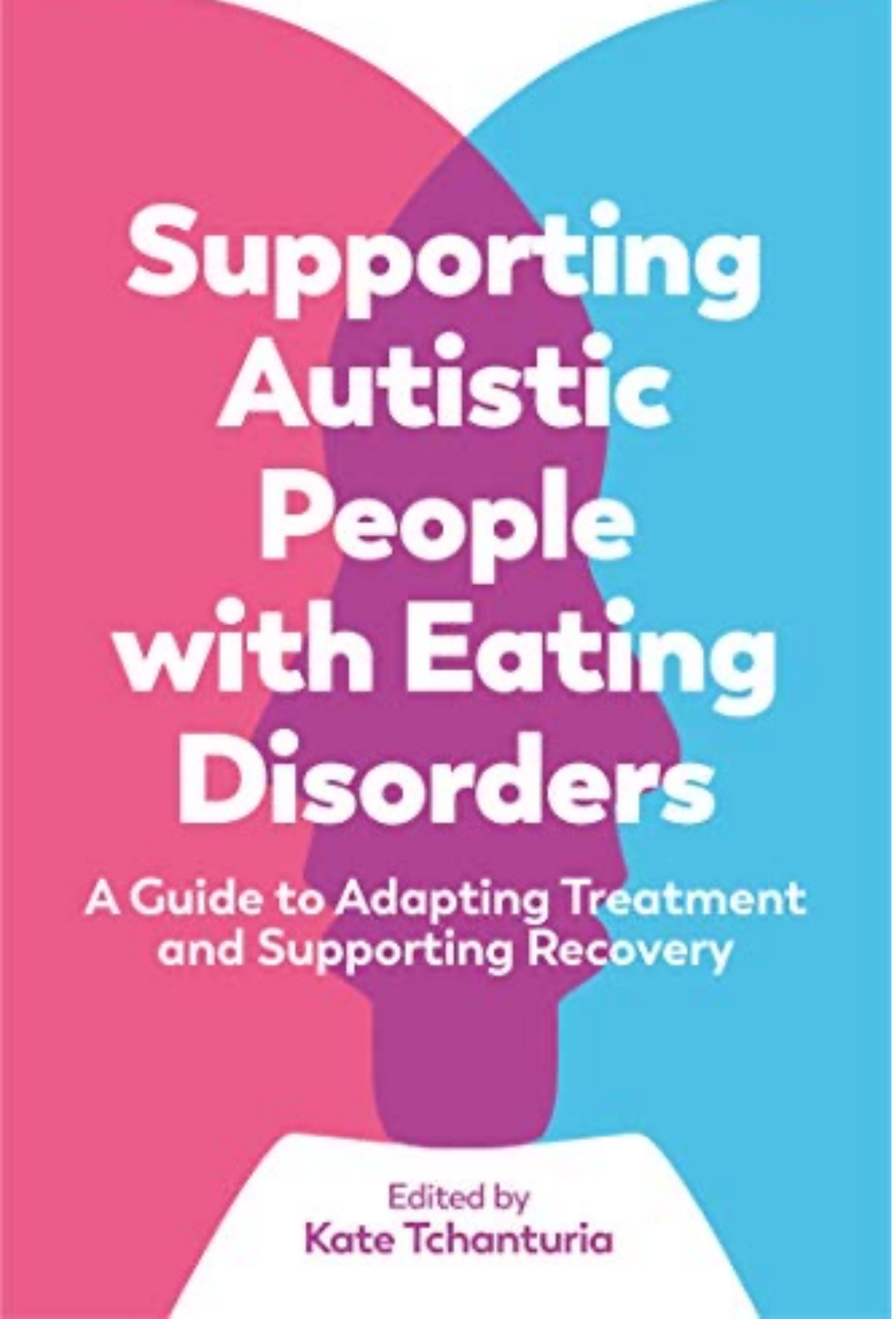
Backing Better Mental Health.



Supporting Autistic People with Eating Disorders

A Guide to Adapting Treatment and Supporting Recovery

Edited by
Kate Tchanturia

The paradox of being a carer & Expressed Emotion (EE)

- My personal experience and professional understanding of EE is what made me think I had something to contribute to the research field of family carers of those with mental health problems:
- I've written about this in the chapter: 'Making the 'mental transition' from clinician to carer: the importance of Expressed Emotion' (Oakley 2021) from the book published in April this year:

  'Supporting Autistic People with Eating Disorders' (2021)

  Edited by Kate Tchanturia
- Family carers often need to be emotionally overinvolved as the complex nature of the cared for person's problems mean that a high level involvement is necessary both for their daily care and also to deal with the statutory processes of accessing appropriate diagnoses and services.

However, lower levels of EE benefit both carers and the person they are caring for.

The impact of the pandemic on carers and those they care for: my lived experience

- The first UK lockdown from March to July 2020 seemed novel in the beginning – not going out except for essential journeys, and the curtailment of most face to face activities. My son and those he shared a house with accepted the restrictions obediently. Now a year and a half and two further lockdowns later, most of the residents have developed new mental and physical health problems.
- The family carers (of whom I am one) have had to become more involved with their loved ones and their care, to keep them as stable psychologically as possible. So my point is, once you are an autism parent/carer, you always will be, as autism is a lifelong neurodevelopmental condition where the person with autism experience challenges at every life cycle stage, and when the unexpected happens such as in the Pandemic, new and added pressures will be felt by carers.

Background

> "Sufferers of concurrent autism and eating disorders make up at least 35% of all sufferers of anorexia. (Tchanturia 2021, Westwod & Tchanturia 2017)"

> "As autism is a lifelong condition, carers of family members with this comorbidity will face challenges at all life cycle stages. (Myers et al 2009)"

The research I will present follows on from the 2020 paper from our PEACE team:

Carers' views on autism and eating disorders comorbidity: qualitative study (2020)

Adamson, Kinnaird, Glennon, Oakley & Tchanturia

- The carers experienced high levels of unmet needs, a perceived lack of support from existing services, and subsequent feelings of isolation and frustration
- This group might benefit from support designed specifically for carers of people with autism and EDs.

The next study

A peer interview qualitative study exploring support for carers of people with comorbid autism and eating disorders

Kinnaird, Oakley, Lawrence, Shergill , Tchanturia (2021)

Peer-led

Carer interviews conducted by myself (an autism family carer)

Engaged fathers and carers of males with the comorbidity

as well as female carers of females

Interviewed during lockdown

A snapshot of how the early months of the Pandemic impacted on carers

Methods

Peer conducted interviews

Semi-structured peer interviews

with carers of people with ED and autism

Questions asked about

- Carers experiences of getting assessments and help for their children
- Experiences of getting help as carers
- Any improvements in services they would recommend for their loved ones and themselves as carers

11 carers participated

- Data analysed using Thematic Analysis
- 7 participants discussed the impact of lockdown

Themes

The following five themes were identified:

- **Challenges associated with co-occurring autism and EDs**
- **Lack of existing support**
- **Impact on carers**
- **Supporting the supporters**
- **Coronavirus**

Theme 1

Challenges associated with co-occurring Autism and EDs

Nearly all carers described difficulties getting an autism diagnosis for their loved one, or their child's autism being overlooked

- All carers recalled that their loved one only received an autism diagnosis *after receiving treatment for mental health problems, most commonly AN*
- Delayed recognition of autism resulted in later problems due to a *lack of appropriate early support*

Theme 2

Lack of existing support

Lack of help or support from services

- Loved one ***not*** receiving support/treatment that considered the complexities associated with their autism.
- In particular, ED treatment services lacked experience in adapting care for patients with autism. One carer described ED treatment as designed “for neurotypicals… it doesn’t take into account the autism”.
- Consequently, carers described having to take an active role in **advocating for their child to receive appropriate care.**

Theme 3

Impact on carers

Burden of care

- Closely interlinked with Theme 2: **Additional needs associated with autism and EDs** *and* **a lack of appropriate service provision** create a significant burden of care, and dominating carers' lives and identities:

“It’s all-consuming, it doesn’t leave you time to think about much else”

- Financial impact: giving up their job to care for their child, or seeking private treatment
- Adapting their lives around the ED in fact ***reinforced the ED itself***:

“We are ingraining his problems. We have given him what he wanted. It’s like scraping and scraping a piece of wood. We have fed and been a martyr to his problems”

Theme 4

Supporting the supporters

Recommendations for changes

- Improved and tailored treatments, primarily focused around adapting ED treatments for needs associated with autism, including:
  - Training in autism for ED clinicians
  - More personalised approaches
  - Accommodating sensory needs in meal plans, including help for carers with meal support in their homes and a 24/7 helpline for autism/ED carers
- Interventions designed to help the carers themselves, such as:
  - Psychoeducational strategies around concurrent autism and EDs
  - Peer-based support
  - Clear signposting of additional sources of help

Theme 5

Coronavirus

Seven out of the eleven (63%) participants mentioned the impact of the COVID-19 pandemic

- Negative impacts:
    - loved ones’ treatments being suspended, disrupted or moving online
    - increased carer responsibilities in helping with their child’s treatment
    - difficult to obtain preferred foods and brands in shops due to stock shortages
    - both they and their child were experiencing worsening social isolation

Conclusions

Replication of the finding (Adamson & Kinnaird et al 2020) that:
Patients, carers and clinicians in this field do require ***specialised adaptations and tailored treatment***

Rather than focusing on clinical service-provided interventions for carers, ***peer-based support*** for carers could be particularly beneficial.

It is possible that ***peer-based support and mentoring, and further peer led research*** (Devotta et al 2016) could be helpful for this population.

The following slides present one such peer-led intervention for PEACE carers – *online coffee groups.*

Online PEACE coffee groups for families with autism and eating disorders during the Covid-19 pandemic

(2021 Oakley, Biggs, Carr, Toloza & Tchanturia)

- **A weekly peer-led online coffee group**

  Weekly; time-limited - 8 months duration; Carers could attend when it was convenient for them

- **Safety and Confidentiality**

  Groups had a ‘secure base’ model (Bowlby 2005) and were confidential

- **Checking in**

  Carers would each be invited to ‘check in’ about how they were feeling at the beginning of each group. Thereafter, the carers spoke spontaneously, with the group leader aiming to ensure that each participant had a chance to talk.

- **Joining process**

  The group leader shared the fact that she was also an autism carer, as part of the ‘joining process’ (Minuchin 2012)

Themes

from the feedback on coffee groups

- **Theme 1: Experiences of caring for someone with an ED and ASC**

  Sub themes: Not feeling supported; needs not being met; isolation felt by carers
  In the groups, carers said that they were able to discuss their high levels of isolation and their feelings of not being supported.

- **Theme 3: The value of the online carers' coffee groups**

  Sub themes: The value of shared experiences and not being alone; emotional support and reassurance; problem-solving & learning from other peoples' experiences

- **Theme 2: Lack of support from outside of the group**

  Sub themes: Professionals' lack of understanding; lack of appropriate services and resources for ASC/ED carers

- **Theme 4: Suggestions & future needs**

  Sub-themes: the importance of continued supportive spaces for carers to meet and share experiences; the need for future learning opportunities for carers

Reflections

on the carers’ coffee groups

People with autism have suffered from higher levels of anxiety and restrictions placed on their routines during the Pandemic (National Autistic Society 2021)

Carers who are looking after family members with EDs and comorbid ASC are facing even greater challenges in caring for their loved ones who now have increased mental health problems as a result of the Pandemic.

Following the ending of the PEACE online coffee groups, the carers who attended have kept in touch with each other and provided mutual support via a WhatsApp group which was set up by the carers themselves.

A limitation of the coffee groups could be that they were a short-term intervention.

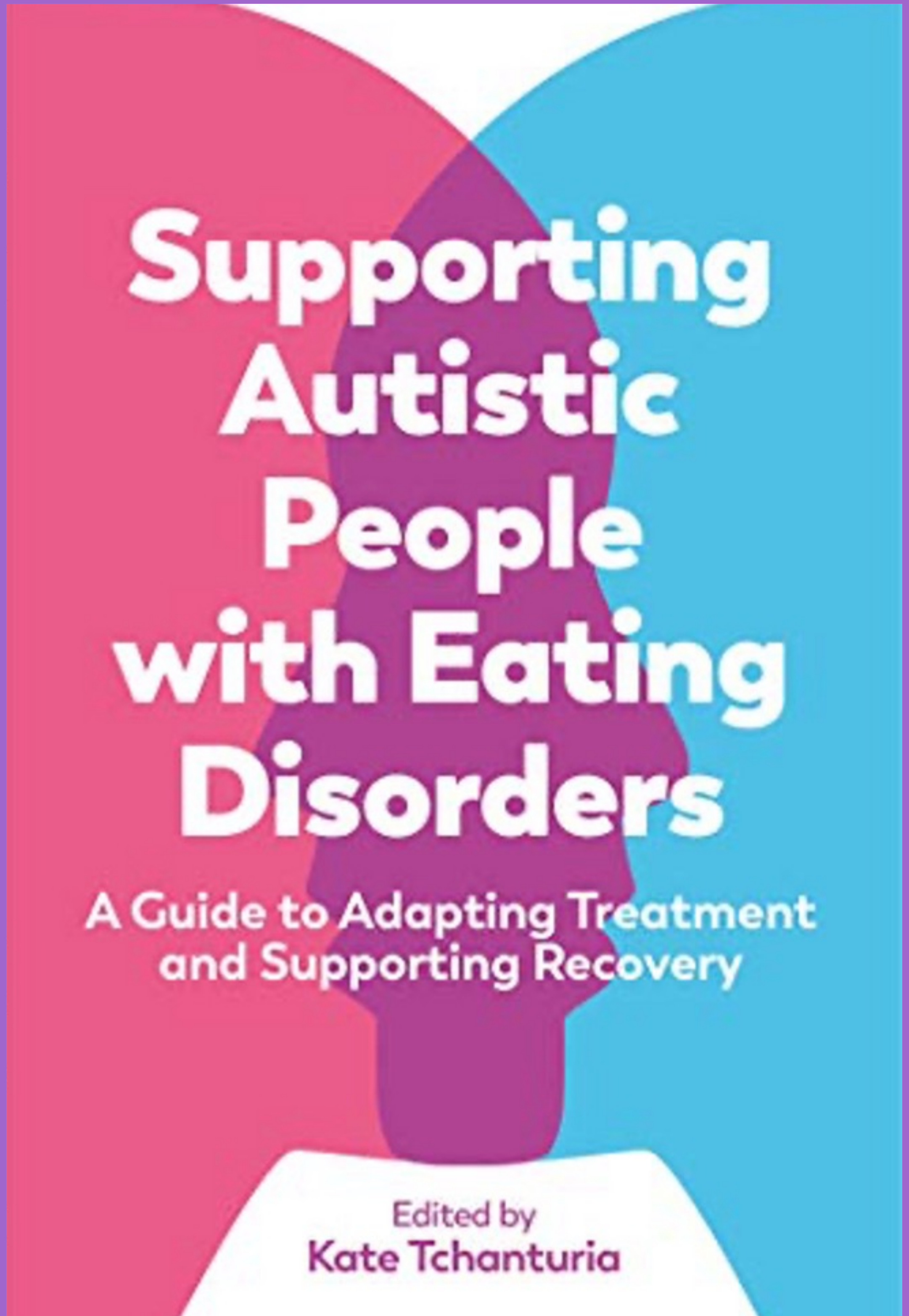
Future research ideas

for PEACE Pathway carers

The need for permanent peer-led support for carers of family members with EDs and ASC has been now established by PEACE Pathway researchers
(Kinnaird & Oakley et al., 2021 & Oakley et al. 2021).

Evaluating the online coffee groups has stimulated ideas about future developments: facilitating further peer-led networks of carers who can support each other online and feel less isolated.

Tailored workshops offering skills training and supportive networks will be offered via the PEACE Pathway project in 2022 to carers of family members with autism & EDs.



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Thank you!

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References:

Kinnaird E, Oakley M, Lawrence V, Shergill S & Tchanturia K. (2021)
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