# Working with family carers of people with autism and eating disorders on the PEACE Pathway

PEACE

Pathway for Eating disorders and Autism developed from Clinical Experience

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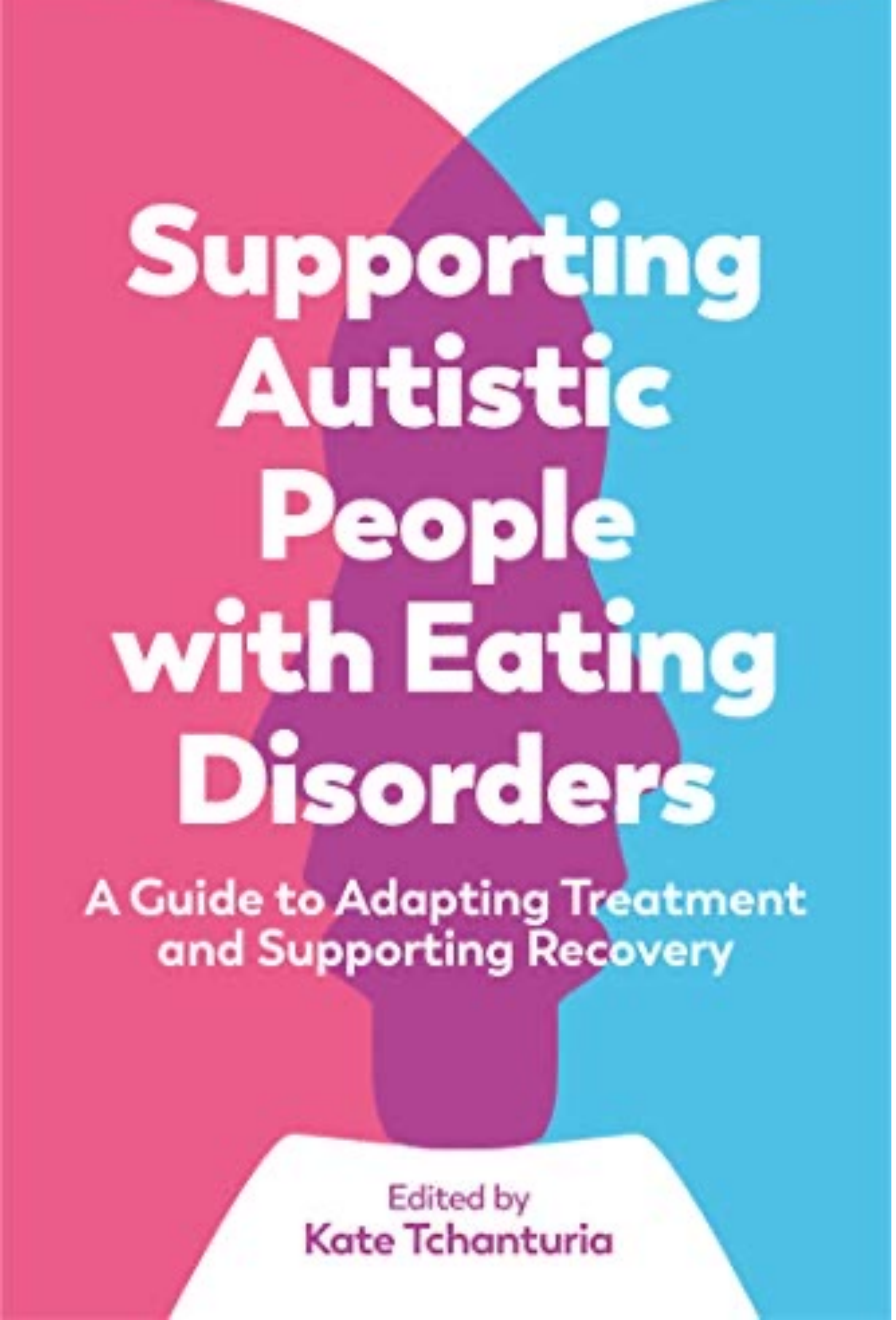

Supporting Autistic People with Eating Disorders

A Guide to Adapting Treatment and Supporting Recovery

Edited by
Kate Tchanturia

# My own carer journey

- My personal experience as an autism- carer and systemic family therapist made me think I had something to contribute to designing support and psychoeducation for family carers.
- I’ve written about this in the chapter: ‘Making the ‘mental transition’ from clinician to carer: the importance of Expressed Emotion’ from:

‘Supporting Autistic People with Eating Disorders’ (2021)

Edited by Kate Tchanturia

# My research and its aims (2019-present)

- Title: ‘Developing online interventions for families with autism spectrum condition and concurrent eating disorders’
- To examine and explore the needs and experiences of family carers of people with concurrent autism and eating disorders by interviewing them
- To offer carers of people with autism and eating disorders, online support-groups and online psychoeducational workshops
- To evaluate the support groups and workshops and then implement subsequent interventions which respond to the findings in the data

# Background

- 2 papers by PEACE Pathway team (Adamson et al 2020, Kinnaird et al 2021) told us the following:
- Carers wanted tailored interventions for their loved ones and tailored support for themselves (Adamson et al 2020)
- Carers expressed frustration with existing ED services, feeling not listened to
- The second study (Kinnaird et al 2021) replicated the findings of the previous study (Adamson et al 2020).
- The interviews in the second study were conducted by a peer-carer (myself), during the first year of Covid-19, and also included male carers' perspectives. These carers asked for peer-led support and interventions.

# Methods

**5 support groups were offered online 2020-2023**

- **Study 1** - first weekly online support group for autism-ED carers via PEACE Twitter page (9 carers weekly for 9 months in 2020)
- **Study 2-** second weekly online support group for SLaM & St George's autism-ED carers (5 carers weekly for 5 months in 2021 - 22)
- **Study 3** - online psychoeducational workshops followed by support groups for autism-ED carers via PEACE Twitter page (7 carers weekly over 4 weeks; in 2022)
- **Study 4** - online support groups for autism-ED carers via PEACE carers contacts (14 carers monthly over 6 months; in 2022-23)
- **Study 5** - psychoeducational workshops followed by support groups for carers of people with autism & other comorbidities via Twitter (24 carers weekly over 4 weeks; in 2023)

# Results

- Study 1 - Carers felt supported by the online group; ‘not alone’; got emotional support & reassurance; learnt from others’ experiences; wanted ongoing support and tailored psychoeducation for themselves. Formed their own What’s App group. Findings published in (Oakley et al 2021)
- Study 2 - Online groups gave carers hope, more confidence and a sense of optimism; felt less isolated and in a safe place where they could learn from and build relationships with each other. Liked the online format & small size of the group. Carers became friends outside the group.
- Study 3 - Carers valued the format and content of the online workshops, which were followed by online support groups. Areas covered: the value of low Expressed Emotion; Non-violent Resistance (NVR) in de-escalating conflicts, the importance of support networks for carers & carers self-care.

# Results

- Study 4 – Larger group meant that carers found this less supportive; not enough time for everyone to talk. Difficult to hear about others' adverse experiences. However, group was inclusive & non-judgemental; skilled facilitation; carers formed a What's App group when the group ended. Asked for future talks on specific themes as well as future support.
- Study 5 - Carers valued the format and content of the peer-led workshops, followed by the support groups. Psychoeducational workshops covered: Acceptance & Commitment Therapy principles (recognising and accepting what you can and can't change); importance of low Expressed Emotion, Non-violent Resistance & carer self-care. Carers reported enjoying connecting and sharing experiences, knowledge and resources with each other. The carers had a dissatisfaction with services, feeling that there was a general lack of autism awareness. Carers kept in touch with each other according to different comorbidities, via What's App and in-person.

# Conclusions

- Carers preferred smaller groups for getting emotional support.
- Larger groups were helpful for psychoeducational workshops and sharing specialist information and also for carers feeling that they were not alone. Carers wanted more knowledge about the comorbidities and also recognised that they were resources for each other, often having niche knowledge.
- Carers created What's App groups to keep in touch with each other after all of the groups finished.
- All autism-ED carers wanted continuing peer-led psychoeducational workshops on specific topics, followed by peer-led support groups for carers of people with the same comorbidities

# Recommendations

- Autism has a large number of comorbidities. Patients (with autism & eating disorders), and with autism and other mental health conditions, and their carers, would benefit from support being tailored for specific comorbidities
- Carers’ negative experiences with services (for not being ‘autism-friendly’) indicate that clinicians (and carers) would benefit from autism training (and learning more about its comorbidities).
- If autism-aware protocols and strategies were adopted in mental health provision, these service users may have better outcomes. Their carers may feel less stressed and more part of the triangle of care, and less that they have to do battle with services to find the right support for their loved ones.

# Strengths of the research

- Dual identity of researcher offers unique insights about clinical and psychoeducational interventions which might be helpful for carers.
- Qualitative findings were captured, analysed, implemented, and then evaluated.
- Interviews and feedback from the groups gave a picture of carers' experiences during the different stages of the Covid-19 Pandemic. Carers were used to having restricted lives and recognised their own resilience: saying that now 'everyone is locked down, not just us'.
- Carers maintained supportive contact with each other following the interventions.

# Limitations of the research

- Small sample sizes of each study, (though 86 carers in total).
- Possible pro-carer bias as researcher is also a carer; this could have been counter-balanced by collaborating with other researchers in our lab who were not carers.
- Service users being looked after by carers had a combination of formal autism diagnoses and presumed autism, though all had ED diagnoses
- Covid-19 Pandemic could have exacerbated the hardships faced by carers, as their loved ones were sometimes more distressed, and less help and resources were available, to support patients and carers.
- As I am a peer-carer and also a clinician, this may be difficult to replicate.

# Clinical implications and future research

- Autism needs to be demystified to professionals and carers, in particular when treating patients with comorbidities
- Autism-friendly protocols (such as has been developed in the PEACE Pathway) could be developed for other clinical treatment pathways such as: Early Intervention for Psychosis, and Early Intervention for Eating Disorders
- Autism-friendly protocols could be developed for the support and psychoeducation for carers of people with autism and eating disorders, autism and psychosis and other autism-comorbidities
- In summary: caring for a family member with autism (and comorbidities) may be a lifelong role. More interventions are needed to support adults who have autism (and other comorbidities) and their carers.

# Recommendations

- Further peer-led support groups and psychoeducation, for carers of family members with concurrent autism and eating disorders, could be developed. Carers also suggested mentoring schemes for themselves. All interventions and resources need to be made easily accessible for carers.
- Many interventions exist for carers of children with autism but few for carers of adults with autism, most of whom will have comorbid conditions. Models of support and psychoeducation could be developed for these carers.
- The profile and confidence of autism-ED family carers could be developed, so that they are more recognised by clinicians and services as partners and part of the Triangle of Care (Worthington et al).

# References

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# Thank you!

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