

Involving Carers and Supporters in the PEACE Pathway

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Talk Map

- Our provision
- How we've understand the challenges
- The adaptations we've made
- Plans for the future

ADD YOUR IDEAS IN THE CHAT:

What might be some of the challenges experienced by carers where there's ASD and an eating disorder?



Our Provision for Carers

- Carers/supporters are a vital resource in eating disorder recovery
- NICE Guidelines recommend they receive information and support
- New Maudsley Model: <https://thenewmaudsleyapproach.co.uk/>
- Individual support for carers, with or without their loved one
- Individual support for the patient to develop their social skills and ability to make use of their social network in recovery
- Carers' workshops to share information and help supporters to develop communication skills using Motivational Interviewing

What We've Learnt from Working Together

- Carers have shared concerns about not only supporting a loved one with an eating disorder, but also other comorbidities
- These commonly include depression, anxiety, OCD and autism spectrum disorder
- They want help and information about these co-occurring challenges

Key Challenges and Strengths: ASD

CHALLENGES

- Late/no/mis diagnosis
- Lack of community services/ongoing support on discharge
- ADIs: Difficulties present from early in the lifespan and have contributed to, or been exacerbated by/entwined with the eating disorder
- Not all families identify with the diagnosis even if traits are present – stigma?

STRENGTHS

- ASD traits might be present in other family members – greater understanding and resources
- Getting a diagnosis can provide new insight for carers into their loved one's difficulties and offer new ways to approach offering support – a “lightbulb moment”

How We've Adapted our Practice

- Include ASD challenges in the comorbidities we consider in the carers' workshop
- Attend to these challenges more when working together
- Incorporate ASD traits into our shared conceptualisation of the illness, not just how it affects the person, but how others respond to it
- In some cases – the main challenge is the ASD, so if we work on this, the eating disorder symptoms may subside
- Produced a new carers' pathway handbook which considers sensory differences and is more accessible

BEFORE

Further Sources of Support and Information

Beat:

<https://www.beateatingdisorders.org.uk/>

Adult Helpline: 0808 801 0677

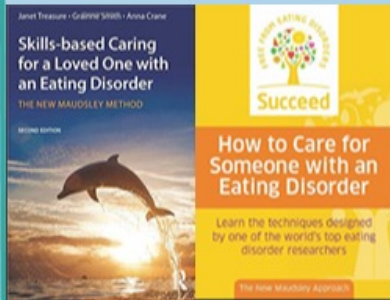
Studentline: 0808 801 0811

Youthline: 0808 801 0711

Helplines are open 365 days a year from 12pm – 8pm during the week, and 4pm – 8pm on weekends and bank holidays.

Email support: help@beateatingdisorders.org.uk

Book and DVD Recommendations:



Get Involved

To join our Service User and Carers' Advisory Group, please email caroline.norton@slam.nhs.uk


South London and Maudsley NHS Foundation Trust



Carer Pathway

South London and Maudsley NHS Foundation Trust Eating Disorder Services

This handbook is for carers whose loved ones are accessing inpatient, daycare, outpatients, Step-Up treatment programmes to explain to you how we support you throughout our services.

Welcome!

You're reading this handbook because you are a family member, friend, colleague or neighbor of a loved one with an eating disorder whose illness has meant that they have needed to enter one of our treatment programmes. The purpose of this handbook is to share information with you about how we support you as carers of a loved one with an eating disorder.

Our team have led a number of large research studies which have shown that caring for a loved one with an eating disorder can be really challenging and this caring role can be time-consuming and have an impact on wellbeing. Our research and clinical experience show that when we involve carers in our patients' care, this not only helps the patient themselves, but it also helps carers to manage their role and take care of themselves.

When you are on the airplane, you are advised to put on your own oxygen mask first before helping others. Our work with carers shows how important it is to help yourself first with knowledge, skills and self-care to equip you to support your loved one.

Carers' Workshops

We offer workshops for carers where we share information about eating disorders and train you in professional skills that our research and clinical experience have shown help with communication and supporting a loved one with an eating disorder. These one day workshops are held between 9.45am and 4pm in the Education Room next to the Canteen at the Bethlem Royal Hospital and are cofacilitated by professionals from our team and a person who has accessed our services and is in recovery from an eating disorder. **Upcoming dates: 8th Nov 2019, 13th Dec 2019.** Please email amy.harrison@slam.nhs.uk to let us know you're coming

Carers' Support Groups

On the last Wednesday of every month we host a **Carer's support group at 5.00pm-18:30pm**. There is no need to reserve a place and all carers are welcome. These groups are held at the Maudsley Hospital outpatient eating disorder service in Middle House.

Carers' Assessments and Referrals

We can refer you for a Carers' Assessment which can help with the financial costs of being a carer, depending on your circumstances. We can also refer you to services to help you with your own mental health.

Transition Planning

Eating disorders can last for many years and this may mean that patients need to move between services (e.g. from child and adolescent to adult services, from inpatient to outpatient services) in order to best support the person. We will work with you and your loved one and other services that might be involved in their care to help with these transitions. This will include encouraging your loved one to involve you in treatment, care planning meetings, ward rounds and case management meetings. We will collaborate with you around on how best to support your loved one with this transition and will work together with you to set up plans and backup plans to support around recovery, symptom management, lapses and relapses.

Family Therapy and Family Support Work

In our inpatient, outpatient and day care services, we can offer therapeutic meetings with yourself and your loved one to help you think about and work on your relationships and the impact of the eating disorder on your family and network. We can also offer support for you on your own to help you with your experiences of caring for a loved one with an eating disorder.



Carer Pathway Handbook

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AFTER

Transition Planning

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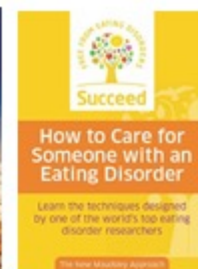
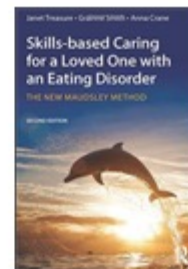
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National Autistic Society: www.autism.org.uk

Book and DVD Recommendations



PINK FLAMINGO METAPHOR



- Vocal – carers have to speak up for loved ones
- Skittish – run away and hide – anxiety/stress
- Move location when resources are lacking

Clinician Reflections

- Be curious about the presence of ASD traits but avoid jumping to conclusions
- Explore developmental history with parents or other informants using the ADI
- Be inclusive and consider neurodiversity in interactions with carers
- Be open and honest about what is and isn't available
- Help the support network to develop a shared understanding of ASD and how best to respond and help

THANK YOU

Further Reading: Supporting Autistic People with Eating Disorders (Ed: Kate Tchanturia) Section 4, page 97: Adapting carers' interventions for families where eating disorders and autism spectrum conditions coexist

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YouTube: Science of Eating Disorders: <https://tinyurl.com/scienceofed>