Case Studies and Effective Approaches

Case studies and models identified across London have shown that a joint approach between teams is needed to best meet the needs of young people with disordered eating. The principles below have been developed to support those working in both mental and physical health teams, to help services to consider their teams' capacity and confidence to support young people presenting with disordered eating, and to consider their links with system partners and other teams to facilitate a joint approach. Joint working is especially important to ensure that mental and physical health risk is managed by appropriate teams and facilitates support and interventions to take place.

Different approaches to joint working and the teams who need to be involved will vary depending on the young person's presentation. Assessment and treatment planning should be holistic; including an assessment of mental health covering history of other disorders, young person's developmental history, family history and social context. The case studies below highlight effective practice for young people with disordered eating.

Case studies and models of practice from across London

Case study one: Joint working between crisis team and community ED service

Area where implemented: Adolescent Community Treatment Services (ACTS) team in Central North West London NHS Foundation Trust (CNWL)

Presentation: Disordered eating and dysregulation or emerging emotionally unstable personality disorder (EUPD)

Teams involved: This work was led by the ACTS team at CNWL which provides an alternative to admission support. They drew on support from their local CYP community eating disorder service and discharged to the community CAMHS team.

Approach to care: For dysregulation/emerging EUPD, the ACTS team use a Dialectical Behavioural Therapy (DBT) and family therapy approach to focus not just on the eating issues but also on the underlying mood instability and any self-harm or suicidal ideation.

Presentation:

- Young person with history of emotional dysregulation, self-harm, and disordered eating
- Previously known to both eating disorders service and CAMHS
- Discharged from an inpatient setting and supported in the community, under the home treatment team, with care coordination (safety planning, risk monitoring, managing physical health, liaison with network, school reintegration), family therapy and individual and group DBT
- Disordered eating was targeted on the DBT hierarchy of risks and monitored as such. Through DBT, the young person learnt skills to manage distress, regulate emotions, and manage interpersonal difficulties
- CED team supported the home treatment team in a consultation role, advising around physical health monitoring and investigations
- Young person was open to the home treatment team for six months before being discharged to CAMHS

- By discharge from home treatment to community team, the young person was maintaining a stable healthy weight and self-harm had reduced in frequency and severity.

Case study two: Joint working between paediatric service, acute adolescent unit, and community eating disorder service

Area where implemented: South West London and St. George's Mental Health NHS Trust

Teams involved: Paediatrics ward led with support from community eating disorder team and joint working with tier 4 General Adolescent Unit

Presentation: Disordered eating, dysregulation, and autism spectrum condition

- Fifteen-year-old with symptoms including self-harm, impulsive behaviour, low mood, restricted eating and longstanding sensory issues and cognitive rigidity. History of low mood managed as a depressive episode, multiple episodes of ad-hoc contact for self-harming, and not meeting screening criteria for an ASD assessment. The young person reported that they had not found contact helpful
- History of longstanding limited diet, beige foods, little enjoyment of food, rigid patterns of eating
- In addition, since starting treatment, the young person would try to go for long periods of not eating and there had been recent weight loss. Parents felt unable to manage at home due to concern about both suicidal ideation and eating
- The young person was admitted to the paediatric ward. Unhappy on ward, did not like food or environment, refused to eat and unable to engage in discussions about why. This progressed to NG feeding tube (NGT)
- A phased transition between paediatric ward and Tier 4 General Adolescent Unit (GAU) was put in place. The young person would return to the paediatric ward twice a week for NG feeding but was supported to quickly re-establish normal eating without specific eating disorder treatment apart from general support with eating on the GAU, and the teams shared the risk and responsibility for four weeks to enable safe transition to the community
- Over the next several weeks, there was a better understanding of their needs, including socio-communication difficulties and frequent misinterpretations leading to significant conflict and meltdowns at home, emotional dysregulation, with restriction as a coping strategy leading to entrenched patterns of food refusal as part of a way of managing emotions, on the background of longstanding sensory issues with food and eating in the context of ASD.

Case study three: Shared mental health and paediatric guidelines for presentations to acute hospitals

Area where implemented: South West London and St. George's Mental Health NHS Trust

Teams Involved: Guidance developed to support paediatric teams following young people presenting with disordered eating in the community or acute hospital with food and fluid avoidance

Approach to Care: During the peak of the pandemic, South West London & St George's Mental Health Trust and St George's Hospital acute Trust developed an interim guideline (see figure 1) for management of young people presenting to acute paediatric services with disordered eating. This was in response to an escalation in the presentation of young people admitted onto paediatric wards for acute food restriction and refusal, quickly leading to restrictive practice with NG tube feeding under restraint used without a plan of how to stop this. Some young people's presentation worsened after admission to inpatient eating disorder units, and it was subsequently concluded that there was not a primary anorexia nervosa, or that an eating disorder was present but was not the primary problem driving the presenting behaviours.

This guidance is being used to ensure that:

- Diagnosis of eating disorders are not given prematurely in complex cases with diagnostic uncertainty until there is a formal assessment
- Young people are assessed holistically and mental health needs apart from eating disorders are considered carefully, even if the presenting problem is with an eating disturbance
- Admissions to paediatric wards are avoided where possible, in favour of medical monitoring in the community which can be used to support more appropriate mental health support
- Young people with significant mental health and psychosocial needs are not forced into escalating eating behaviours, particularly where this leads to prolonged inpatient admissions with NG tube feeding under restraint.

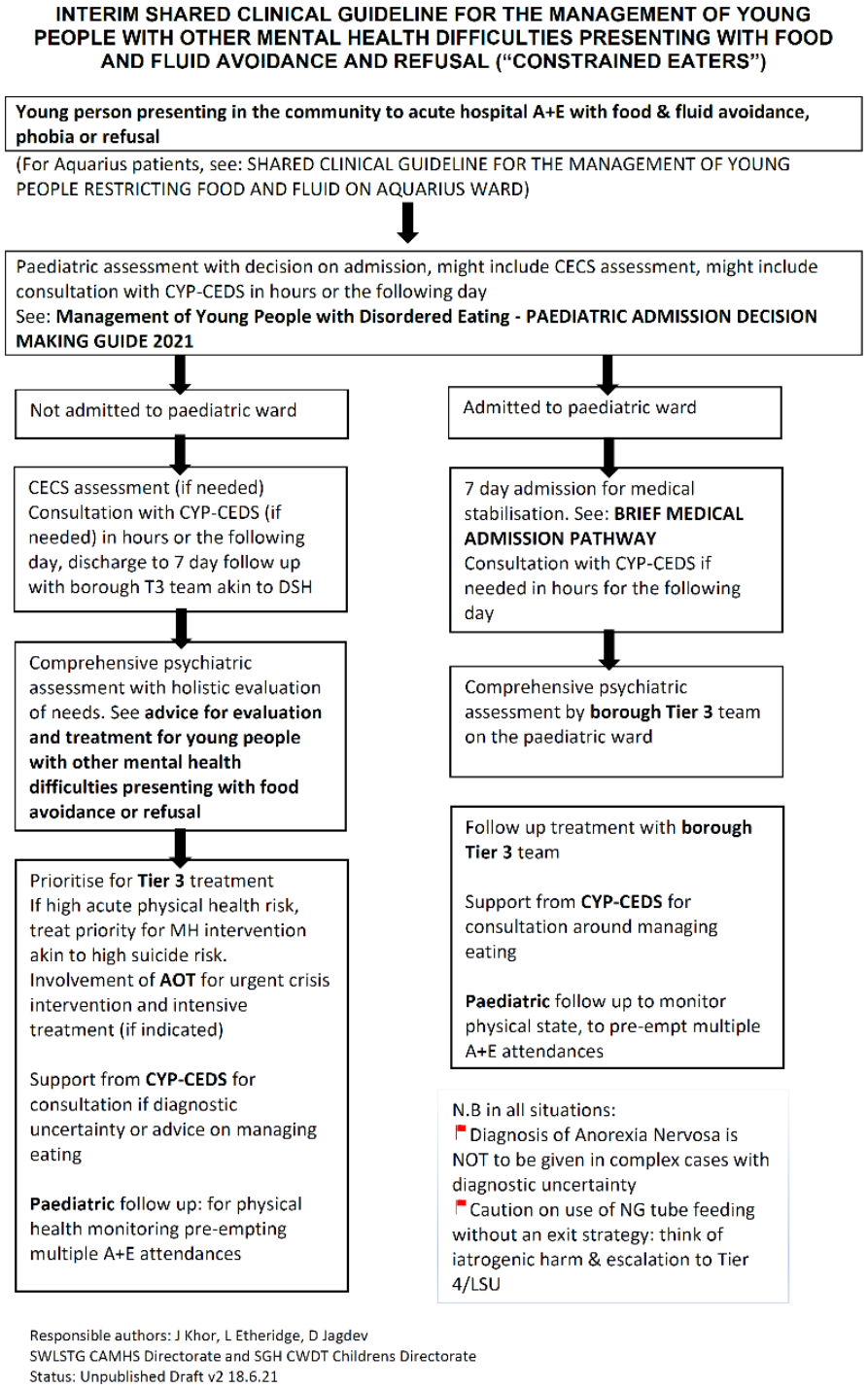

Figure 1: Interim shared clinical guideline

Please note:

1. These are interim guidelines intended to make the most of a situation of high demand during Covid, and where services were not ideally or adequately commissioned to meet the needs of CYP presenting with eating disturbances in general, and atypical eating disturbances in particular. Areas with more commissioned provision already should take this into account in developing their pathways. There should be continued advocacy to adequately resource mental and acute health services to deliver high quality services with the right specialist skills for young people presenting with eating disturbances of all sorts. This might include, for example, ARFID teams / pathways, intensive support for young people with emotion dysregulation and those on the autism spectrum.

2. The terms used in these guidelines are meant to be easily accessible to multiple agencies including professionals who are not experts in mental health and eating disorders and are meant to be descriptive rather than read as new categories. Mental health and eating disorder services should use DSM-V and ICD-11 diagnoses and diagnostic process.

3. The primary intentions of these guidelines were to avoid undesirable outcomes for young people, particularly NG tube-dependence and prolonged Tier 4 admissions, and inhibited access to appropriate treatment for their other mental health needs. They are meant to increase cooperation between services where presentations fall outside of the remits of all services as they understand them. There are not meant to increase the polarisation of positions of services and exclusion of young people from all services and should not be used that way.

4. Extreme care and sensitivity should be used in communicating with young people and families.

4. Effective Approaches

To effectively support young people with disordered eating, service leads should consider their teams' skills, capacity, and confidence in meeting the mental and physical health needs of young people with this presentation. This also includes owning and managing mental and physical health risks. Below are factors for services to consider when applying joint approaches to care planning and in developing local pathways.

Referral, Assessment, Triage

It is important to raise awareness of disordered eating with those referring and assessing young people.

- Early recognition is important. Referrers should not automatically assume an eating disorder
- Care and sensitivity should be used in communicating with young people and families
- Manage the expectations of young people and parents/carers around what care and treatment they might receive. Presenting an alternative formulation should not be a rejection of care provision, but rather a clarification of what more targeted care will look like, and to the level of intensity required given the need
- For complex or unclear cases, please refer to the definition and patterns of behaviour for disordered eating. Also liaise with wider teams including CAMHS, CEDS if need more advice
- Admission to inpatient settings can cause an escalation. Where possible try to access home or community treatment
- If a young person needs to be admitted, work towards a short stay and consider an exit strategy especially if NG feeding is needed

Joint working approaches to care planning

To best meet the needs of young people with disordered eating, joint working approaches are needed to ensure both physical and mental health needs are being met. Cases are often complex and support from several teams might be needed. Outlined below are a series of questions for services to consider in developing or adapting pathways.

- How confident is your staff team in developing care / treatment plans for young people presenting with disordered/constrained eating? Does this include joint working approaches?
- For mental health teams, how confident is your team around managing physical health risk?
- For physical health teams, how confident is your team around managing mental health risk?
- Do you have links with or a good working relationship with your Community Eating Disorder Service?
- Do you have links with or a good working relationship with a paediatric team or GAU?
- Do you have links with or a good working relationship a neurodevelopmental (ASC) team?
- Do you have links with or a good working relationship with teams providing DBT?

- How confident is your team in providing support to families which includes psychoeducation?
- How confident is your team in working with wider teams to provide a consistent approach across all settings?
- Do you need to complete additional mapping of available support in your area?
- Do you need to build stronger working relationships with other teams to facilitate better joint working?
- Do you have links with or good working relationship with additional agencies including children's social care, VCSE, schools to develop a multi-disciplinary approach.
- The increasing presentations of disordered eating might also highlight the need for more intensive targeted services for particular groups, e.g. intensive support for young people with ASC presenting in crisis, and e.g. easily accessible DBT services for young people presenting with emotion dysregulation.

Training

Services should also consider what skills, training and or additional support would help their team to better support a young person with this presentation. See the training directory and resources accompanying this guidance.