Disordered Eating in Children and Young People – Guidance for Health and Care Professionals

September 2022

Aims

This guidance document has been developed to support health and care professionals to better meet the needs of young people with disordered eating. We hope it will also help to raise awareness with parents, carers, teachers, youth workers, and other groups. This work aims:

- to raise awareness and understanding that not all young people presenting with disordered or constrained eating necessarily have an eating disorder
- to ensure those referring and assessing young people consider the underlying causes and do not focus solely on eating, and;
- to facilitate joint working approaches between physical and mental health teams, as well as between inpatient, community, and home treatment teams.

Background

In autumn 2021 a working group was established to explore the rise in presentations of disordered eating in children and young people, aiming to develop a set of principles to care for this patient group. This request arose from concerns about the increasing numbers of young people presenting with disordered eating in community and inpatient settings. The group comprised of experienced clinicians and experts by experience who came together to explore key clinical questions regarding how best to care for this patient group. Members of the group are noted in the acknowledgements section of this document.

This guidance document outlines the outcomes of those discussions and provides a suggested approach to meeting the needs of young people with disordered eating. We hope this work builds wider understanding around these complex presentations, and will lead to more detailed assessments, better-informed referrals, and better treatment more tailored to the individual needs of the young person. In addition, we hope services can develop or adapt their local pathways and include a joint working approach to care planning that better meets the needs of young people.

We understand and acknowledge that the term “disordered eating” has been used in many contexts. For the purposes of this work, we are referring to young people with disordered eating who do not have a diagnosable eating disorder such as Anorexia or Avoidant restrictive food intake disorder (ARFID), but who might have other mental health difficulties and psychosocial challenges. Eating disorder focused treatment and admission can often lead to an escalation in the presentation and a worsening clinical picture. This is often a

difficult group to identify, and the treatment interventions required are very different to those indicated for diagnosed eating disorders, making it important to identify disordered eating as early as possible.

Contents

1. Guiding principles

Assumptions – do not assume that all young people who are restricting their eating have an eating disorder. Eating disturbances of all sorts, including restricted eating or acute food refusal, may be features of a range of patterns of difficulties.
Referral, assessment, and treatment – planning should be holistic including an assessment of mental health covering history of other disorders, young person's developmental history including feeding/eating history, family history and social context, rather than just focusing on eating.
Joint working – for this group, labelling a young person as having an eating disorder before this is clear, and focussing too quickly on a plan of eating disorder-focused treatment and inpatient admission, can be ineffective and may lead to an escalation in the presentation. Instead, joint working approaches are recommended for care and treatment. This includes mental and physical health teams as well as between inpatient, community and home treatment teams. This approach can help teams to confidently manage both the mental and physical health risks presented by young people with disordered eating.
Admission – when possible, support from home treatment teams or community teams and avoidance of psychiatric inpatient admission are recommended. Nasogastric tube (NG tube) feeding can result in increased length of stay. Where inpatient stay and NG tube feeding is needed, it is strongly recommended that there is a clear plan in place to discontinue its use.
Communication – ensure you communicate effectively with the young person and parents/carers throughout the referral, assessment, and treatment process. This can help the young person and parents/carers feel more involved and aware of what is happening and when. Regular communication can make a big difference.
Expectations – it is important to manage expectations of young people and parents/carers so that they aren't expecting a specific diagnosis or treatment pathway. Not

being accepted into a service or not getting the diagnosis you were expecting can be very difficult.
Support – getting an unexpected diagnosis or treatment pathway may leave a young person feeling invalidated or rejected, and that what they are going through is less serious and less deserving of treatment. It is important to support young people through this, but also to emphasise that their needs are as important and they are as deserving of help, and to ensure that they are able to receive the intensity of support they need for any other identified needs.
Additional resources – double check with young people and parents/carers that they have access to, and can engage with, any additional resources or training. This should include those that are waiting to access treatment and throughout the treatment and recovery process. Examples of resources could include support from Beat, from Voluntary, Community and Social Enterprise (VCSE) in their local areas, access to crisis support and other wellbeing initiatives.
Transitions – can be difficult, whether it is between inpatient and community settings, from adolescent to adult services, stepping down from treatment, or going back into the care of their GP and school. Joint planning and communication with the young person and parents/carer about what to expect at all stages can help them feel more on board with next steps and more confident to move forward.

2. Definition and patterns of behaviour

Language and definition

We understand that there is some confusion around the term disordered eating which has been used in several contexts. For the purpose of this work, we are using the term disordered eating to mean eating behaviours of all types, including restricted eating and acute food refusal, which when properly assessed do not constitute a primary eating disorder such as anorexia nervosa, bulimia nervosa, binge eating disorder or ARFID. This group of young people may often have other mental health difficulties or psychosocial challenges; for example emotional dysregulation, where disordered eating behaviours may be one of the ways used to modulate distressing emotional states. Eating disorder-focused treatment or admission may lead to an escalation in the presentation and a worsening clinical picture.

A key aim of this work is to raise awareness and understanding that not all young people presenting with disordered eating necessarily have an eating disorder. It is important for those referring and assessing young people to consider what is driving and maintaining the eating behaviour. In cases of disordered eating, it can often be a symptom relating to either their neurodevelopmental needs, or in the case of dysregulation, part of alternating patterns of disordered eating behaviours, self-harm, and other impulsive behaviours used as a means of managing distress.

Patterns of behaviour

It is important for those referring and assessing young people to not automatically assume an eating disorder when disordered eating is observed, but to consider other possibilities in a comprehensive and holistic formulation.

Outlined below are some common patterns of behaviour seen with young people presenting with disordered eating. The information focuses on autism spectrum condition and emotional dysregulation / emerging emotional unstable personality disorder (EUPD). The examples below explore patterns of eating and possible drivers for this.

Autism spectrum condition

Possible patterns to look out for:

- Acute food / fluid refusal in response to a crisis (can be severe, with medical consequences)
- Pre-existing patterns of picky or faddy eating, preference for beige foods, narrow or idiosyncratic diets (assessment for ARFID might be indicated)
- The crisis may have been provoked by any number of challenging contexts that the young person is unable to tolerate and may seek to avoid. The severity of the crises may be exacerbated by rigid, black-or-white thinking, challenges with understanding social context and negotiating peer or family relationships, and/or challenges with understanding and communicating thoughts and feelings effectively to resolve interpersonal conflict.

Emotion dysregulation / emerging EUPD

Possible patterns to look out for:

- Acute food / fluid refusal in response to a crisis (can be severe, with medical consequences)
- Alternating patterns of eating behaviours, self-harm, and other impulsive behaviours (symptom-substitution patterns or disorganised patterns)
- Can be in response to perceived rejection / abandonment
- May be in the context of going to extreme lengths to be or feel part of a group
- Used to modulate emotions, or has that effect unintentionally
- May be an alternative to severe self-harm or other risk-taking behaviour (may happen when trying to reduce these behaviours, e.g., when starting a new treatment).

Other issues to be aware of

- There may be a discrepancy between what is reported and evidence for the reality of this
- There may be difficulty engaging with the support offered, and behaviour patterns which lead to increased anxiety in professionals and carers
- There may be an escalation in impulsive or risk-taking behaviour in response to perceived rejection or abandonment, e.g. when a primary eating disorder diagnosis is not made, and similarly there may be an increase in risk to self when there are attempts to remove the NG tube or increase the meal plan.

3. Case studies and models

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.

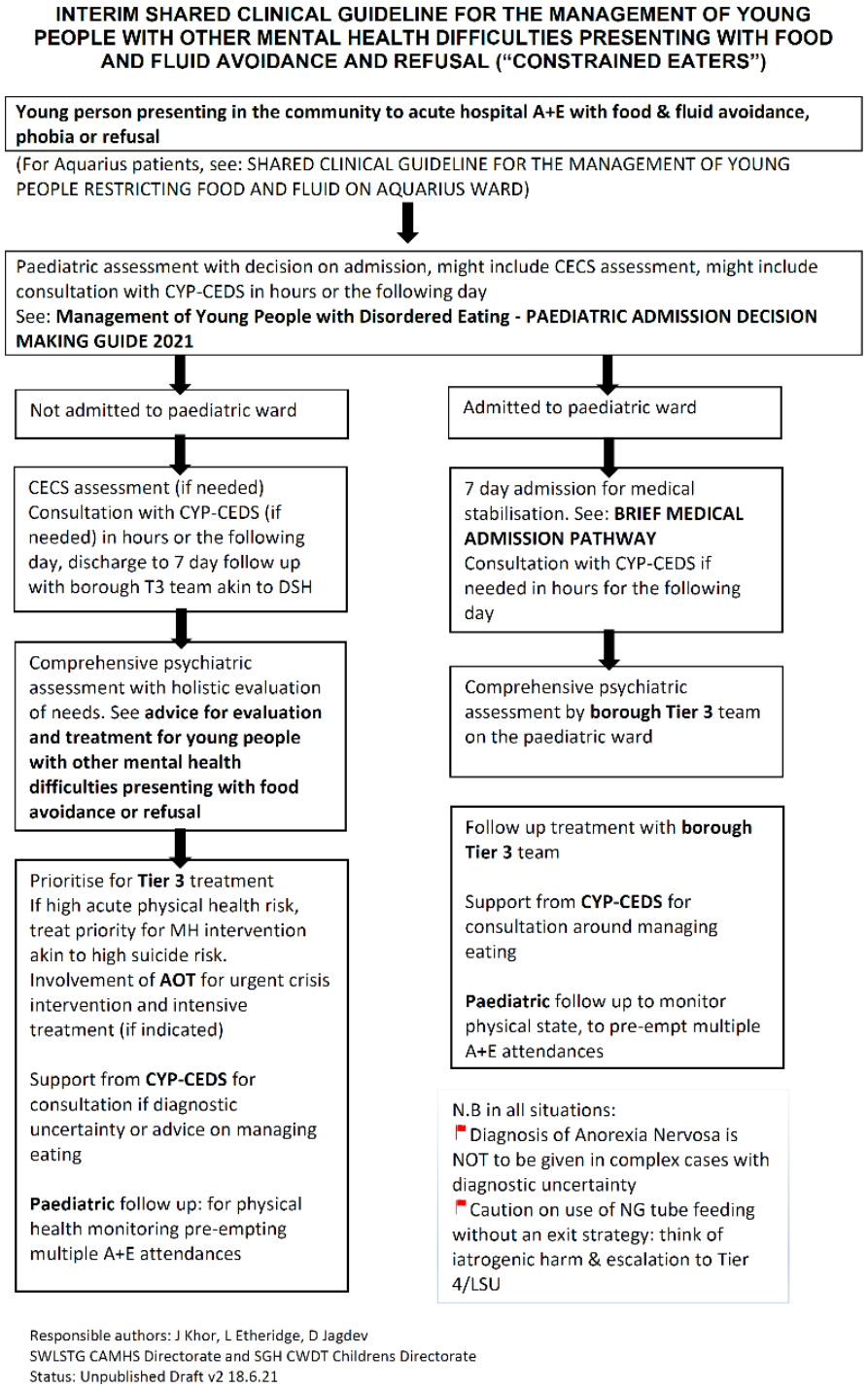

Figure 1: Interim shared clinical guideline

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.

5. Training and resources

- Health Education England Eating Disorders training directory
- Healthy London Partnership disordered eating webpage, including bite-sized elements from the guidance:
  - case studies and effective approaches
  - definition and patterns of behaviour
  - guiding principles.
- General mental health support via Good Thinking

6. Final thoughts from experts by experience – young people and parents

- It is important that young people and families are not told that an eating disorder diagnosis is going to be the result of any assessments or referrals. This will help with managing expectations so they are not necessarily expecting to receive a diagnosis of an eating disorder and treatment through an eating disorders team. This is often mistakenly seen as the best treatment option and makes it difficult if other treatment (CAMHS/home/community) is recommended, and especially difficult if the diagnosis is not for a primary eating disorder
- It is important that one diagnosis or treatment pathway isn't seen as more valid or serious than another. The young people who have been presenting with disordered/constrained eating are often very unwell and we have seen this presentation escalating when they are admitted to medical settings
- It is also important that young people feel validated and understand the seriousness of their presentation. Young people might be expecting an eating disorder diagnosis and then feel unvalidated, confused, or rejected if they receive another diagnosis. They then might also feel that what they are experiencing is less serious.

7. Acknowledgements

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Dr Annie Cardinal, North East London Foundation Trust

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Dr Erica Cini, East London NHS Foundation Trust

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Dr Luci Etheridge, South West London & St. George's Mental Health NHS Trust

Dr Joel Khor, South West London & St. George's Mental Health NHS Trust

Dr Cathy Lavelle, North Central and East London CAMHS Provider Collaborative

Polly Lee, North Central and East London CAMHS Provider Collaborative

Dr Dorothy Newton, West London NHS Trust

Carol Nolan, West London NHS Trust

Dr Gin Peh, Barts Health NHS Trust

Dr Ria Pugh, CAMHS South London and Community Mental Health Partnership Provider Collaborative

Dr Rafik Refaat, North Central and East London CAMHS Provider Collaborative

Alan Strachan, North Central East London CAMHS Provider Collaborative

Dr Sarah Sturrock – South West London & St. George's Mental Health NHS Trust

Dr Emily Turton, South London Partnership

Dr Mamta Vaidya, Barts Health NHS Trust