Wandsworth Mental health GP Afternoon 8/11/2018

Eating disorders in young people: the patient and family journey and the role of primary care

South West London CYP-CEDS
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Beat
Eating disorders

Delaying for years, denied for months

The health, emotional and financial impact on sufferers, families and the NHS of delaying treatment for eating disorders in England

Before realising they had an eating disorder

- The longest delay to treatment is the period before recognising the signs and symptoms of an eating disorder.
- People wait on average three-and-a-half years between falling ill and starting treatment.

Between realising and seeking help

- On average, it takes people over a year to seek help after recognising the signs of an eating disorder.
- Adults wait twice as long as under 19s.

TOTAL 176 weeks

Average time (weeks) spent waiting for eating disorder treatment

Between first GP visit and referral

- Only 14% of people are referred within four weeks of their first GP visit.
- Men and boys wait 28 weeks for a referral compared to 10 weeks for women and girls.
- *We had been to the GP quite a lot of times. They just kept saying it is her age and she is going through puberty...* Father

Between referral and assessment

- *I got referred to CAMHS and, I guess, they diagnosed me and then they didn't actually call back for another year and a half...* Sufferer
- 25% of sufferers aged 19 and over were referred to non-specialist services.

Between assessment and start of treatment

- For 27% of people, treatment did not begin for over three years after their symptoms emerged.
- Less than 50% of patients received all the information they need about eating disorders, their treatment, and sources of extra support.

Impact on families

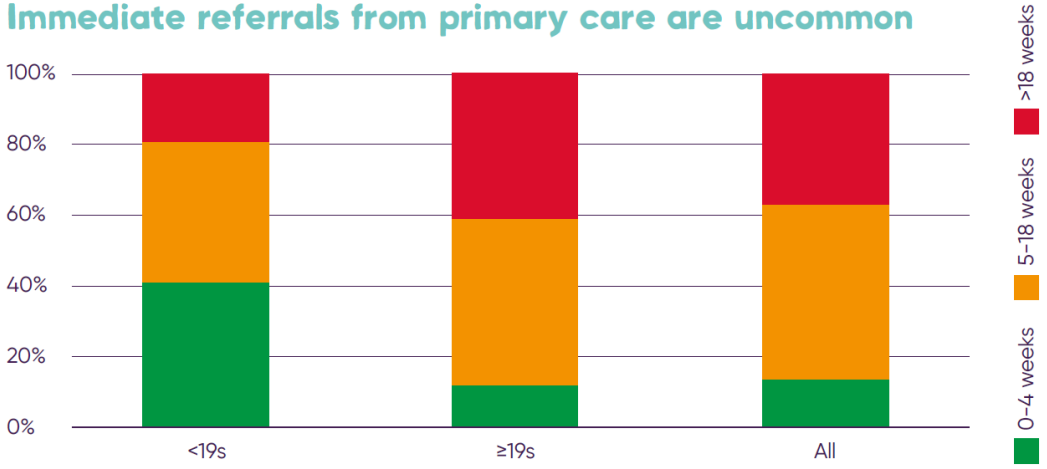
- On average, carers spent £32,672 as a result of their loved one's eating disorder.
- *It's just like it's destroying the whole family... our other two kids, they're older, and they can hardly come home.* Mother

TOTAL 130 weeks

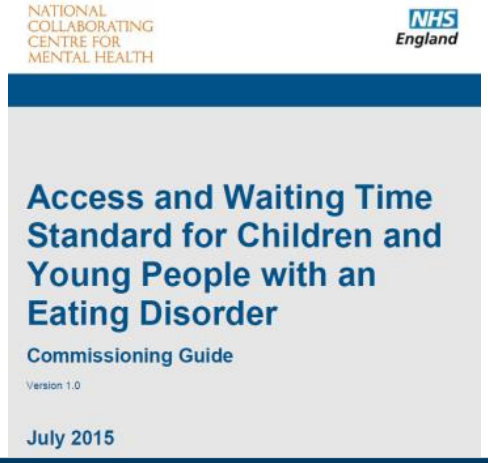
Average time (weeks) spent waiting by under 19s for eating disorder treatment

- Before realising they had an eating disorder
- Between realising and seeking help from GP
- Between first GP visit and referral
- Between referral and assessment
- Between assessment and start of treatment

Immediate referrals from primary care are uncommon



Proportion of people waiting different lengths of time between the first discussion with their GP and treatment starting.



It is vital that children and young people with eating disorders, and their families and carers, can access effective help quickly. Offering evidence-based, high-quality care and support as soon as possible can improve recovery rates, lead to fewer relapses and reduce the need for inpatient admissions.

Healthy London Partnership

Eating Disorder Summary Guidance (Children and Young People) for primary care professionals

Purpose

This document is derived from NICE[1] and NHS England guidance[2]. The aim of this summary document is to provide Primary Care professionals with an evidence-based resource to enable further support children and young people (CYP) aged up to 18 years who have (or are suspected of having) an eating disorder.

The sooner someone with an eating disorder starts an evidence-based NICE-concordant treatment the better the outcome. The standard is for treatment to be received within a maximum of 4 weeks from first contact with a designated healthcare professional for routine cases and within 1 week for urgent cases. In cases of emergency, the eating disorder service should be contacted to provide support within 24 hours.

Refer ALL young people with suspected Eating Disorders to your local Community Eating Disorders Team

Referral information

When to refer

Low weight
Losing weight
Anxiety about gaining weight
Bingeing, purging, overexercising, misuse of laxative, diuretics
Physical or psychological symptoms that may indicate an ED

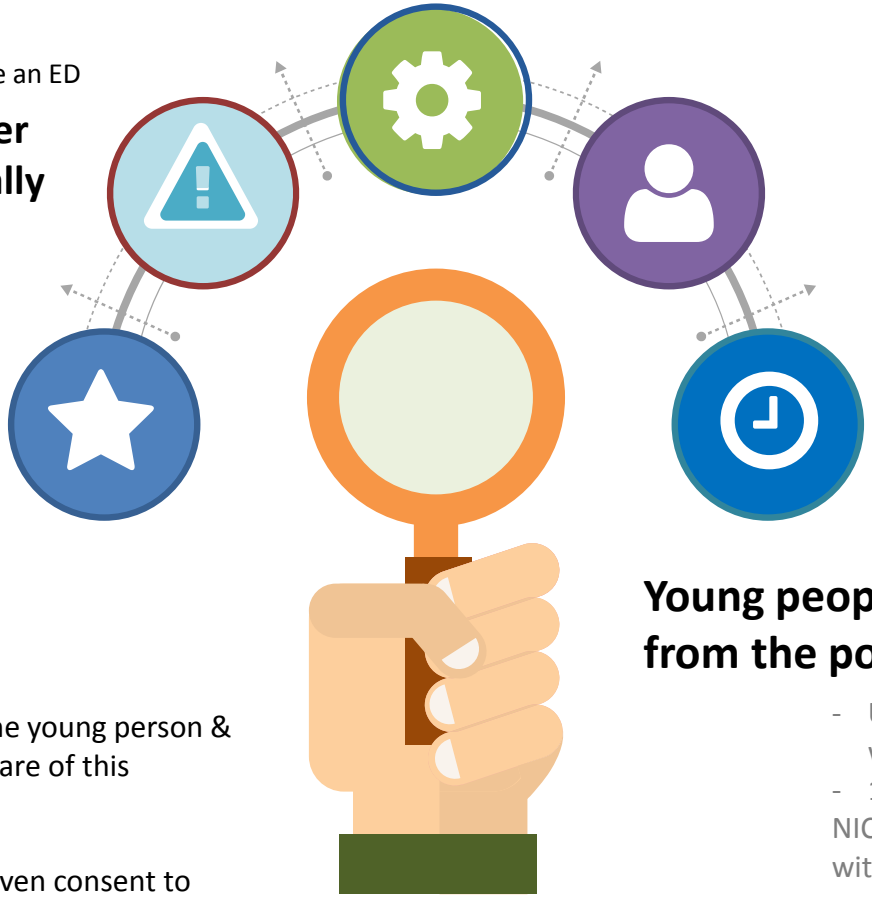
Include the physical exam

IF PHYSICALLY COMPROMISED FOLLOW ACUTE PAEDIATRIC PATHWAY

Young people no longer need to be exceptionally underweight before referral

Low weight is now defined as a loss of 10% of a young person's expected body weight

<u>Refer YP who are normal or overweight but suspected of having an eating disorder and losing weight or bingeing / purging</u>



Consent

Are both the young person & parents aware of this referral?

Who has given consent to this referral?

Young people will be seen quickly from the point of referral

- Urgent assessment will be within 5 days
- 15 days if routine

NICE concordant treatment with 28 days

Eating disorders.
Know the first signs?

Lips

Are they obsessive about food?

Flips

Is their behaviour changing?

Hips

Do they have distorted beliefs about their body size?

Kips

Are they often tired or struggling to concentrate?

Nips

Do they disappear to the toilet after meals?

Skips

Have they started exercising excessively?

If you're worried someone you care about is showing any signs of an eating disorder – even if they're not on our list – act quickly and get in touch. We can give you the answers and support you need to help them on the road to recovery as soon as possible.

Don't delay. Visit beateatingdisorders.org.uk/tips

Beat
Eating disorders

Beat is the UK's eating disorder charity. We are a champion, guide and friend for anyone affected by an eating disorder.

Online support

Visit beateatingdisorders.org.uk for information about eating disorders, message boards, online support groups and one to one chat.
Use helpfinder.beateatingdisorders.org.uk to find services in your area.
@BeatEDSupport BeatEDSupport

General enquries

Unit 1, Chalk Hill House, 19 Rosary Road, Norwich NR1 1SZ
0300 123 3355 | beateatingdisorders.org.uk
info@beateatingdisorders.org.uk
@beatED beat.eating.disorders

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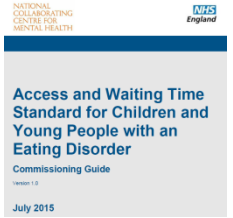
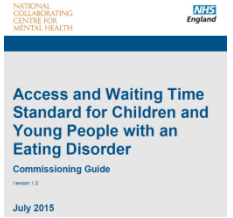
GP referral to CEDS-CYP



- This is an established referral route; however, a *new requirement* will be for the GP to contact the eating disorder service via telephone or electronically following discussion with the child or young person and their parents or carers, as soon as an eating disorder is first identified.

- The CEDS-CYP should log the date of referral and the *CLOCK STARTS* at this time.

GP conducts an assessment



The GP should assess physical health and look for any other signs or symptoms that suggest high risk

- Acute physical compromise may need paediatric input more urgently
- High psychiatric risk (for example, suicidal), local risk management protocols should be followed
- Urgent presentations (but at a level of risk that has not required immediate action) should be offered assessment with the CEDS-CYP as soon as possible and *within 5 days from the clock starting*
- Routine presentations should be offered an assessment with the CEDS-CYP *within 15 days of the clock starting*
- The child or young person should be monitored by the GP on a weekly basis until the assessment appointment. If their condition deteriorates, a more urgent appointment will be offered.

Junior MARSIPAN Risk Assessment Framework

RISK ASSESSMENT FRAMEWORK FOR YOUNG PEOPLE WITH EATING DISORDERS				
	RED (High risk)	AMBER (Alert to high concern)	GREEN (Moderate risk)	BLUE (Low risk)
Body mass	Percentage Median BMI (see section A1 for calculation of %BMI) <70% [Approximates to below 0.4th BMI centile]	Percentage Median BMI 70-80% [Approximates to between 2nd and 0.4th BMI centile]	Percentage Median BMI 80-85% [Approximates to between 9th and 2nd BMI centile]	Percentage Median BMI >85% [Approximates to above 9th BMI centile]
	Recent loss of weight of 1kg or more/week for two consecutive weeks	Recent loss of weight of 500g-999g/week for two consecutive weeks	Recent weight loss of up to 500g/week for two consecutive weeks	No weight loss over past two weeks
Cardiovascular Health	Heart rate (awake) <40 bpm[1]	Heart rate (awake) 40-50bpm	Heart rate (awake) 50-60bpm	Heart rate (awake) >60bpm
		Sitting Blood Pressure Systolic <0.4th centile (84-98mmHg depending on age and sex[2]) Diastolic <0.4th centile (35 -40 mmHg depending on age and sex1)	Sitting Blood Pressure Systolic <2nd centile (88 - 105mmHg depending on age and sex1) Diastolic <2nd centile (40 - 45mmHg depending on age and sex1)	Normal sitting blood pressure for age and sex with reference to centile charts1
	History of Recurrent Syncope Marked orthostatic changes (fall in systolic blood pressure of 20mmHg or more, or below 0.4th-2nd centiles for age, or increase in heart rate > 30bpm)	Moderate orthostatic cardiovascular changes (fall in systolic blood pressure of 15mmHg or more, or diastolic blood pressure fall of 10mmHg or more within 3 mins standing, or increase in heart rate up to 30bpm) Occasional syncope	Pre-syncopal symptoms but normal orthostatic cardiovascular changes	Normal orthostatic cardiovascular changes
	Irregular heart rhythm (does not include sinus arrhythmia)			Normal heart rhythm
			Cool peripheries. Prolonged peripheral capillary refill time (normal central capillary refill time	
ECG abnormalities	QTc > 460 ms (girls) or 40ms (boys) with evidence of bradyarrhythmia or tachyarrhythmia (excludes sinus bradycardia and sinus arrhythmia) ECG evidence of biochemical abnormality	QTc >460ms (girls) or 40 ms (boys)	QTc < 460ms (girls) or 40ms (boys) and taking medication known to prolong QTc interval, family history of prolonged QTc or sensorineural deafness	QTc < 460ms (girls) or 440 ms (boys)
Hydration Status	Fluid refusal Severe dehydration (10%): Reduced urine output Dry mouth Decreased skin turgor, sunken eyes Tachypnoea Tachycardia[3]	Severe fluid restriction Moderate dehydration (5-10%): Reduced urine output Dry mouth Normal skin turgor Some tachypnoea Some tachycardia3	Fluid restriction Mild <5%: May have dry mouth Or not clinically dehydrated but with concerns about risk of dehydration with negative fluid balance.	Not clinically dehydrated
		Peripheral oedema		
Temperature	<35.5oC (tympanic) or 35.0oC axillary	<36 oC		
Biochemical Abnormalities	Hypophosphataemia Hypokalaemia Hypoalbuminaemia Hypoglycaemia Hyponatraemia Hypocalcaemia	Hypophosphataemia Hypokalaemia Hyponatraemia Hypocalcaemia		

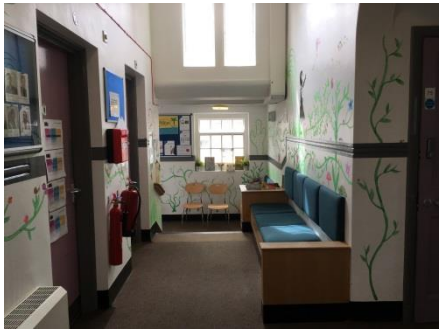
Disordered eating behaviours	Acute food refusal or estimated calorie intake 400-600kcal per day	Severe restriction (less than 50% of required intake). Vomiting. Purging with laxatives	Moderate restriction. Bingeing	
Engagement with management plan	Violent when parents try to limit behaviour or encourage food/fluid intake Parental violence in relation to feeding (hitting, force feeding)	Poor insight into eating problems, lacks motivation to tackle eating problems, resistance to changes required to gain weight. Parents unable to implement meal plan advice given by health care providers	Some insight into eating problems, some motivation to tackle eating problems, ambivalent towards changes required to gain weight but not actively resisting	Some insight into eating problems, motivated to tackle eating problems, ambivalence towards changes required to gain weight not apparent in behaviour
Activity and exercise	High levels of uncontrolled exercise in the context of malnutrition (>2hrs per day)	Moderate levels of uncontrolled exercise in the context of malnutrition (>1 hr per day)	Mild levels of uncontrolled exercise in the context of malnutrition (<1 hr per day)	No uncontrolled exercise
Self harm and suicide	Self poisoning. Suicidal ideas with moderate-high risk of completed suicide	Cutting or similar behaviours. Suicidal ideas with low risk of completed suicide		
Other mental health diagnosis		Other major psychiatric co-diagnosis eg OCD, psychosis, depression		
Muscular weakness SUSS Test	Stand up from squat: Unable to get up at all from squatting (score 0)	Stand up from squat: Unable to get up without using upper limbs (score 1)	Unable to get up without noticeable difficulty (score 2)	Stands up from squat without any difficulty (score 3)
	Sit up: Unable to sit up at all from lying flat (score 0)	Sit up: Unable to sit up from lying flat without using upper limbs (score 1)	Unable to sit up from lying flat without noticeable difficulty (score 2)	Sits up from lying flat without any difficulty (score 3)
Other	Confusion and delirium Acute Pancreatitis Gastric or oesophageal rupture.	Mallory Weiss Tear Gastro-oesophageal reflux or gastritis. Pressure sores.	Poor attention and concentration	

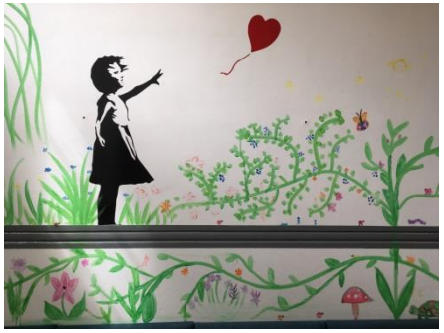
[1] Patients with inappropriately high HR for degree of underweight are at even higher risk (see hypovolaemia). HR may also be increased purposefully through use of excess caffeine in coffee or other drinks.

[2] Jackson L et al. Blood pressures centiles for Great Britain. Arch Dis Child 2007;92:298-303

[3]Or inappropriate normal HR in underweight YP

NHS
South West London and St George's Mental Health NHS Trust





Children & Young Person's Community Eating Disorders Service (CEDS-CYP)

Address: Children & Young Person's Community Eating Disorders Service, Newton Building 5, Entrance 7, Springfield University Hospital, 61 Glenburnie Road, Tooting, London, SW17 7DJ

Telephone: **0203 513 6793** Fax: **0203 513 4469** Email: **CAMHSEatingDisorder@swlstg.nhs.uk**

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The CEDS-CYP offers assessment and treatment for children and young people (under 18) with an **eating disorder**. Under current arrangements, medical management of cases of young people with eating disorders is done jointly between the GP practice and CAMHS, with our service needing to defer to the GP for physical investigations. Please complete the form in full for us to determine appropriateness and urgency. If you have any queries about whether a referral is appropriate, please contact the service.

Referrer's name / service:		Phone Number:	
Address:			

Client name:		NHS No:	
Address:			
		Date of birth:	
Parents' names:			
Parent's telephone numbers	Home: Email address:	Mobile:	

GP/Surgery name:		Phone Number:	
Address:			

Does the client speak English?	Yes	No	Is a translator necessary?	Yes	No
What is the client's preferred language?					
Are both the young person & parents aware of this referral? Who is given consent to this referral? If there is no consent, is information being shared because of safeguarding concerns?					

Reason for referral:	
Brief History of Presenting Concerns:	

Please highlight any risks (to self or others):
Current Medication (+ dose):

Any other services involved?

Any other relevant information (please attach any relevant clinical documentation)

Trajectory of weight

Is weight now stable / falling / increasing (please circle)	Rate of weight loss: kg / week

Records of past height/weight and calorific intake are extremely useful. If approximate please put (approx.)

Date	Weight / Height:	Calorific intake

Eating Behaviours (Please include frequency of behaviours)

Vomiting	Yes	No	**Frequency**
Using laxatives	Yes	No	**Frequency**
Overeating / Bingeing (eating a large amount of food in a short time with a feeling of loss of control)	Yes	No	**Frequency**

Essential Brief Physical Assessment

Weight:	Height:	Temperature:
Signs of dehydration (<5%, 5-10%, >10%)? Dizziness or faintness standing up from sitting?		
Orthostatic hypotension / tachycardia:	Lying / sitting BP:	Lying / sitting Pulse:
	Standing BP:	Standing Pulse:

Age at Onset of Periods:	Periods: Absent / Present / Present but abnormal (please circle)
Comment on pubertal development:	

Essential Baseline Investigations

U&E and bicarbonate (particularly in vomiting/abusing laxatives) – looking for hypokalaemia and alkalosis
Ca, Mg, Phosphate, Iron studies, B12/folate, Vitamin D – looking for deficiencies
LFT – looking for hypoalbuminaemia or high ALT secondary to starvation
TFT, prolactin, serum FSH and LH - can differentiate anorexia from other causes of primary amenorrhoea
Random Glucose – hypoglycaemia (<2.6 mmol/L) is unusual and serious in anorexia
FBC - looking for leukopaenia, anaemia/raised HB, thrombocytopenia
CRP / ESR – to consider other causes of low weight
Coeliac screen – to consider other causes of low weight
ECG – note any arrhythmias; prolonged QTc (normal range <440ms boys and <460ms girls)
*We do not require laboratory test results to process the referral, but these would be helpful for assessment. Please would you kindly let us know the results by fax (020 3513 4469) or letter as soon as possible

If this referral is **urgent** please give reason:	

If you consider this referral an **emergency,** we are happy to discuss the referral with you to think through the best course of action, whether an emergency attendance at A+E is required, and making plans for this if so.

Role of Primary Care - examples of good practice

- GPs ringing when they are worried about a YP presenting with ED, allowing us to assess risk together and plan for the appropriate next step
- GPs who are very helpful and supportive to YP and families, where young people and families report their GP helped them enormously with recovery
- GPs communicating well with the specialist eating disorders service
- GPs being a point of contact for local families and local practices, helping to facilitate early referral to the specialist eating disorders service

Role of Primary Care - recent examples that highlight room for development

- GPs feeling completely deskilled around eating disorders
- GPs not assessing physical state when a young person presents with features of an eating disorder
- GPs not doing bloods tests and ECGs or not communicating these
- GPs not referring YP quickly who are restricting and losing weight, leading to further deterioration and a poorer outcome
- GPs feeling that the referrals process was hard to navigate
- GPs reporting poor communication from CEDS to the GP practice
- Inefficiencies in ordering blood tests and ECGs, and retrieving and interpreting the results in timeframes that fit the guidance standards
- Gaps between commissioner expectations of GPs and what GPs feel is within their remit

Wandsworth GP champion in SWL Junior MARSIPAN group

- Looking to recruit a GP from each borough in SWL to be a champion of C&A Eating Disorders within the CCG
- Focus on educating and advocating to health professionals, to promote good practice in GP practices, representatives / managers in CCG, and local paediatric and mental health services.
- Quarterly or termly meetings, most likely held on the Springfield Hospital / St George's Hospital sites
- Contact camhseatingdisorders@swlstg.nhs.uk for expressions of interest yourself or to recommend a colleague