



Original citation: Burton, Maddie (2020) *Understanding and supporting children and young people with eating disorders*. Practice Nursing, 31 (10). pp. 412-419. ISSN 2052-2940

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Understanding and supporting children and young people with eating disorders

It is important to consider eating disorders in children and young people, why they develop and how they may present in primary care settings. The primary focus of this article will be anorexia; given its seriousness in terms of morbidity, the effects of starvation and Eating disorders can have devastating effects on individuals and families. Maddie Burton explains the crucial role practice nurses can play in identifying and supporting patients

ABSTRACT

*Children and young people's mental health conditions have continued to increase. The NHS Digital 2017 survey found that 1 in 8 children have a diagnosable mental health condition. During the current COVID-19 pandemic numbers are set to increase. Eating disorders make up a relatively small proportion of these statistics but have some of the most devastating effects on individuals and families. Anorexia nervosa, as discussed here, has the highest morbidity of any mental health condition. The issues are complex and a challenge to understand for both professionals and families, over typically a protracted period of illness. However, all work with children, young people and their families presents a 'window of opportunity' in being able to resolve issues within a developmental phase prior to the more concrete adult phase. The risk is highest for young people between the ages of 13–17 years. There are several theoretical models that aid understanding of how and why eating disorders emerge and are maintained. Practice nurses in primary care can have a crucial role in early identification and can be found to be less stigmatising than mental health professionals. Practice nurses can have an ongoing role in remaining involved with the young person and their family and as part of wider specialist support system. **Key words | Eating disorders | Anorexia nervosa | Children and young people | General practice***

It is important to consider eating disorders in children and young people, why they develop and how they may present in primary care and practice nurse settings. The primary focus of this article will be anorexia; given its seriousness in terms of morbidity, the effects of starvation and the requirement for early specialised support. Anorexia nervosa is not a disease of the middle classes as is sometimes thought but crosses all cultural and social backgrounds. It has the highest death rate of any mental illness (Treasure and Alexander 2013). In older adolescent's mortality rates are higher than any other serious chronic disease (Hoang et al 2014). Eating disorders can develop at any age in childhood or adolescence in keeping with other mental health disorders; that is half of lifetime mental health problems (excluding dementia) beginning to emerge by age 14 and three-quarters by the mid-20s

(Department of Health 2011). The risk is highest for young people between the ages of 13-17, (National Institute for Health and Care Excellence (NICE) 2017).

A young person with a developing eating disorder can be reluctant to acknowledge they have a problem (Royal College of Psychiatrists, 2020). It needs to be appreciated this is part of the disease process and not about the individual making a personal choice to that effect. Practice nurses are often on the 'front line' in terms of identifying early warning signs. They can offer an invaluable source of support and help, to the young person and the family. They can monitor thresholds for specialist help and for beginning an assessment and treatment process (Cullen, 2011, Treasure and Alexander 2013).

The NHS Long Term Plan (2019) brings together children and young people's mental and physical health across the NHS including primary care and school nurse provision by 2028 (Royal College of Paediatrics and Child Health, 2020, a). There is likely to be an ongoing role and opportunities for practice nurses in primary care settings to be closely working with school nurses in education settings and child and adolescent mental health services (CAMHS) where relevant.

Practice nurses can have an ongoing role in remaining involved with the young person and their family and as part of the wider specialist support system. They can be key in negotiating other relationships in the system around the young person including both the family and the wider context of the other professionals involved in the young person's care. Following a critical phase, the young person will most likely return to their GP and practice nurse team for ongoing monitoring and therapeutic support.

This can take place over a long period of time. Murray et al (2011) identified that positive nurse-patient relationships will provide a key role in improving self-esteem in their patients with anorexia.

This article will focus on:

- Understanding eating disorders, why they occur in young people together with a look at how the various models used to understand eating disorders interact with each other
- Identifying eating disorders in young people, particularly anorexia, within primary care settings
- Referral to specialist CAMHS

- The practice nurse role in identifying young people presenting with symptoms and ongoing work
- A case study example

Understanding eating disorders in young people

Eating disorders most often develop between 15-35 years. With approximately 0.3%-0.5% of the population up to 18 developing anorexia nervosa it is nevertheless a relatively rare condition. Gender ratio is female-male 4:1 for less than 12 years and 9:1 for age range 13-18 years. (Cullen p.153, 2011). Anorexia has always been considered a predominantly female disorder, borne out by the statistics, nevertheless boys and young men do develop anorexia which practitioners also need to be mindful of. The earlier identification and treatment can start the better the prognosis. However underweight children can be at risk of being unidentified, by clinicians and families, as having a problem (Association for Child and Adolescent Mental Health (ACAMH), 2020, NICE 2017). The Mental Health of Children and Young People in England, 2017 report identified an overall prevalence of 0.4 % with an eating disorder. One in eight 5-19-year olds had a diagnosable mental health condition in 2017 (NHS Digital, 2018).

It is generally considered that eating disorders, as with other psychological disorders and mental illnesses, arise not from a single source but as a combination of theoretical models: *biological/medical, psychological, and social or environmental* factors. It is about the interrelation of these overlapping theories together with risk and resilience factors, as a combination, which lead to understanding and interpreting the causes of eating disorders, and not about a single application of a model. Another useful model to aid understanding is the *4 Ps model* which we will consider below, alongside *biological/medical, psychological, and social or environmental* factors.

Biological/medical theory: Illness is classified according to the International Classification of Diseases (ICD 10; World Health Organisation, 2013) (ICD 11 was published in May 2019 and will come into effect in January 2022). Together with the Diagnostic and Statistical Manual (DSM 5; American Psychiatric Association 2013). The medical model considers that illness is determined by an individual's genetic makeup. Recent research suggests a strong genetic link and pre-disposition. Neuroimaging showed differences in brain structure in anorexia nervosa patients. A body of literature (including Fairburn and Harrison, 2003), has found clinical evidence of brain structure atrophy, termed 'pseudoatrophy', caused by starvation state in anorexia nervosa. Some clinical evidence shows that such brain

abnormalities resolve with eating and weight gain (Drevelengas et al, 2001). This is a positive, hopeful aspect and shows the plasticity of the brain, especially in young people, in terms of making 'repairs'. The supporting research demonstrates that anorexia The supporting research demonstrates that anorexia nervosa is not a lifestyle choice but rather an inherent gene which is most probably present and becomes vulnerable when exposed to and articulated with other factors (Nunn et al 2012).

Psychological theory: There are undoubtedly certain high risks groups. With perfectionism implicated as both a risk and a maintaining factor (Fairburn and Harrison 2003). Activities such as sport and fashion may well appeal to those with perfectionist traits, something about the 'theatre of the body' (McDougall 1989). Typically, young people with anorexia often have 'perfectionist' traits and can be academically high achievers. But they often have low self esteem and find it difficult to express or externalise negative emotions (Dhakras 2005).

Social and environmental theories: Other pre-disposing factors centre on the negotiation of transitional points, for example the negotiation of adolescence in combination with an adverse life event such as becoming looked after, bereavement, parental divorce, or sexual abuse, together with a psychological vulnerability. These are also known as adverse childhood experiences (ACEs). There are similarities with self-harm and suicidal behaviour in that there always is a contextual background of either relationship or attachment difficulties even if they are not immediately apparent. The influence of social and environmental factors, or put simply, 'contextual factors' has become very apparent during the current Covid-19 pandemic and subsequent impact of 'lockdown'. It has demonstrated how significant 'context' is regarding what is going on at any one time in children and young people's lives. Concerns have escalated over children and young people's mental health with support structures, such as school attendance, youth work and outdoor activities disappearing. There will have been and will continue to be increased issues of bereavements and managing transitions. A study commissioned by Young Minds (2020) during this period of immense change found that 83% of respondents (2,111 young people under 25) said the pandemic had made their mental health worse.

The 4 Ps model

Can be helpful in our formulation and understanding of eating disorders in children and young people. (MindEd have a useful exercise re the 4 Ps available from: <https://www.minded.org.uk/Component/Details/447157>).

- **Predisposing** (factors causing them to be 'at risk')

- **Precipitating** (factors that have tipped individual over into having difficulty)
- **Protective** (factors that may help counter or reduce the effects of the predisposing or precipitating factor or that might speed a recovery)
- **Perpetuating** (factors that despite attempts to help keep difficulty going and prevent resolution)

The Nunn et al (2012) research as cited above, underpins the nature vs nurture discussion in that development, mental health, and poor mental health, including eating disorders take place within a contextual combination of inherent characteristics. It is about how these characteristics articulate with both the young person's environment and experiences.

It also undermines an argument often presented; that Western society values and media representations of thin role models and the association with positive attributes of attractiveness and popularity predict development of eating disorders (Stice 2002). Social media and societal attitudes towards thinness are often cited as '*reasons*' but they are not reasons in isolation; but rather they can act as contributing and precipitating factors or triggers.

There are similarities with the 'triggers' or 'precipitating factors' described in relation to suicide attempts and the 'trigger' or 'precipitant' being the reason often given, such as relationship difficulties or bullying (Burton 2014). It must be remembered eating disorders are also a variation of self harming behaviours. Anorexia has previously been referred to as the 'slimmer's disease'. Dieting does not cause anorexia; neither do societal attitudes to 'thinness' but they do seem to become an aspect of contributory, precipitating, and perpetuating factors. These are social/environmental theory factors which would not operate in isolation of psychological and biological models but rather act in combination with contributing factors from all the domains. According to the 4Ps model they would be precipitating factors. The interaction and articulation of these models is unique to everyone in terms of their life story and circumstances, which is the challenge and task to understand.

Risk and resilience model

The nature and process of risk and resilience theory also requires exploration to understand the complex interplay between all these theoretical models.

The risk and resilience model was identified by Pearce (1993 as cited in *Together we Stand* 1995), is still regarded as accurate and even more relevant today during the Covid-19 pandemic and wider implications. Pearce defined three areas of risk which could contribute

to the potential for developing emotional and mental health disorders. These were: environmental/contextual, the family and the young person/child as follows:

Environmental/contextual

- Socio-economic disadvantage
- Homelessness
- Disaster
- Discrimination
- Violence in the community
- Being a refugee/asylum seeker
- Other significant life event

Family

- Early attachment/nurturing problems
- Parental conflict
- Family breakdown
- Inconsistent/unclear discipline
- Hostile and/or rejecting relationships
- Significant adults' failure to adapt to child's changing developmental needs
- Physical, emotional, sexual abuse
- Parental mental and/or physical illness
- Parental criminal behaviour
- Death and loss, bereavement issues relating to family members or friends

Child/young person

- Genetic influences
- Low IQ or learning difficulties
- Specific developmental delay
- Communication difficulties
- Difficult temperament
- Gender identity conflict
- Chronic physical illness
- Neurological disorder
- Academic failure/poor school attendance
- Low self esteem

Resilience factors which can mitigate the risk of mental ill health, as identified by Pearce (1993 as cited in *Together we Stand* 1995), are as follows:

Resilience factors

- Secure attachments
- Self-esteem
- Social skills
- Familial compassion and warmth
- A stable family environment
- Social support systems that encourage personal development and coping skills
- A skill or talent

Despite major adversity, exposure and experience of risk factors many young people cope well despite overwhelming odds. The key is *resilience* which acts as a protective factor. Rutter (1985) and again later in (2006) described this as a dynamic evolving process and that it is not just about static factors. The model of risk and resilience is not based on risk and protective factors in themselves but rather on how they interact. The emphasis is on the process of resilience across developmental pathways. Some young people may tick all the boxes in relation to risk factors being present early on in life. Multiple family transitions can increase risk with a cumulative effect on educational achievement, behaviour, and relationships in general. None of the above risk factors or models occurs solely in isolation, but as a combination of factors from each domain (Burton et al 2014). In terms of the current pandemic resilience is being tested in a climate of the impact on children, families, and support networks with increased bereavement issues and missed milestones. Young people have reported increased anxiety levels with everything now taking place in the bedroom including school, friends, and mental health appointments with the accompanying confidentiality and privacy issues (Royal College of Paediatrics and Child Health, 2020, b).

Identifying eating disorders in young people within primary care settings

There are five main eating disorders:

1. Anorexia Nervosa
2. Bulimia Nervosa
3. Binge Eating Disorder

4. Other Specified Feeding or Eating Disorder (OSFED)
5. Avoidant/Restrictive Food Intake Disorder (ARFID). (ACAMH 2020).

The two most common eating disorders to present in primary care include Anorexia Nervosa and Bulimia Nervosa (Royal College of Psychiatrists 2020). Where food is restricted, avoided, or expunged due to perceived fattening effects. There are similarities and shared characteristics and often movement between varieties of presentations over time. (Cullen 2011 p. 150-151). In current debate is childhood obesity which is now recognised as a significant health risk in the wider public health agenda. Although currently, obesity is seen as more of a by-product of lifestyle choices rather than a mental health problem.

For practice nurses in a position to identify early indicators of anorexia; these might include:

- Restricted eating
- Reduced fluid intake so skin may appear very dry
- Thinning hair
- A change or alteration in eating habits
- Distorted body image so despite looking very thin, the individual considers themselves to be the opposite
- Developmentally underweight
- Weight loss
- A denial of the existence of these factors or that there is a problem.

Diagnostic criteria for anorexia nervosa according to ICD-11 (World Health Organisation 2019), includes the following:

- Significantly low body weight for the individual's height, age, developmental stage and weight history that is not due to the unavailability of food. Individuals are required to be at a significantly low body weight for their developmental stage. If the onset of anorexia nervosa is pre-pubertal puberty becomes delayed or arrested.
- Rapid weight loss and a persistent pattern of restrictive eating. Usually associated with extreme fear of weight gain. Behaviours may include fasting, choosing low

calorie food, excessively slow eating of small amounts of food, hiding or spitting out food and purging.

- Low body weight is over-valued with constant monitoring of calorie content of food. Extreme avoidant behaviours such as refusal of having mirrors at home or wearing tight fitting clothing.

Eating disorders can be one of the most difficult areas in mental health to understand with family and friends feeling frustrated, frightened, and wondering why, in the case of anorexia, the person cannot just eat. Interestingly anorexia has been around for centuries with some historical aspects discussed in Treasure and Alexander's (ch. 3, 2013) text. An earlier traditional view was that re-feeding to a safe weight sees the end of the problem. In reality re-feeding is only the start of what is often a long and complex process involving several interventions and clinical resources over what can be a lengthy and sustained period of time, with an average duration of five years (Treasure and Alexander 2013, ACAMH 2020). It is important to acknowledge anorexia is an immensely powerful illness and it is important to externalize it from the individual rather than seeing the individual or the family as the problem.

Referral to specialist Child and Adolescent Mental Health services

A young person presenting with potential anorexia nervosa will need immediate specialist intervention due to any imminent and emerging medical risks to health from starvation; especially due to the associated critical developmental growth phase of physical and mental health. If development is interrupted by the starvation of anorexia it can lead to ongoing health implications. Even with successful treatment and recovery, patients can be left with long term problems of physical health including osteoporosis, infertility, and depression (Nunn 2013). Therefore, immediate medical and mental health assessment and treatment is required. There is a 'window of opportunity' to diagnose, treat and address at the earliest opportunity. Specialist CAMHS provision varies throughout the country and it is important to know how services are configured in specific locations. Many will have a specific care pathway which will be informative and a useful guide. As a rule of thumb CAMHS are commissioned to provide care for young people of 18 years and under. There is now a move for provision and commissioning of services up to age 25 which is sensible. In most areas there can also be distinct specialist eating disorders services which are usually commissioned for 16 years upwards, but not always. In some areas these would commence at 18 years. If a practice nurse has concerns about a young person discussion should immediately take place between themselves or the GP and a referral to a Child and

Adolescent Psychiatrist in CAMHS to confirm a diagnosis. Most CAMHS would be happy to have a telephone consultation and offer advice if a practice nurse has concerns and this is a useful opportunity for making links with local CAMHS. The earlier referral takes place the better, sometimes young people only get specialist help late on when symptoms are already quite entrenched thus treatment success can be more resistant. In my clinical experience I have come across young people who are severely under-nourished and wasted with poor physical signs, requiring immediate hospital admission. These signs and symptoms have not happened overnight but are the result of an extended period of food and fluid restriction. This can come about due to a lack of specialised knowledge on the part of primary care professionals or simply that the young person and their family have not come into any contact with health services. Sometimes families and professionals do not see the obvious until quite late on.

Case study example

Evie is 15 and comes to primary care for immunisations for her travel abroad on a family holiday. With her mum and brother, they are visiting grandparents in South Africa, a holiday of a lifetime. Evie's parents separated 3 years ago when Evie was 12. Evie is very sporty and plays netball and runs in the school athletics team. At primary school, her hobby was gymnastics which she excelled in. Evie comes along to the travel immunisation clinic with Mum. You notice when administering her injection that she appears to be quite slim and there is quite a bit of loose skin around the injection site. When you last saw Evie, she had quite a bit of 'puppy fat'. Her hair looks quite dry. Evie looks quite different today.

It would be appropriate to ask:

- How Evie is feeling
- Does she know if she has lost weight (it may be appropriate to weigh her and check BMI)
- About her periods; starting/stopping
- What does mum think
- How would her friends describe her
- How are things at school and generally

Based on Evie's and her mum's responses it may be appropriate to request a referral to CAMHS for a medical and psychological assessment. As mentioned above this can be tricky to negotiate with a family as often, they can be in denial but often there can be relief that concerns have been raised. It is also worth considering potential confidentiality issues with both Evie and mum present as at 15, Evie would be considered Gillick competent.

The clues are there. It is about being attentive and curious, noticing changes and then responding appropriately. Remember it is important to always ask 'what has happened to you?' rather than 'what is wrong with you?'

If Evie is considered from the various models contributing to our understanding, just from the small amount of information provided she ticks quite a few boxes:

- *Biological/medical theory*: Evie is within the age range of likely onset
- *Psychological theory*: Evie is in a potentially high-risk group given her sporting prowess
- *Social and environmental theory*: Evie has had to negotiate the transition into adolescence within a context of adverse life experiences (ACEs), in Evie's case her parents separating. We do not know how acrimonious it was or what led up to the separation.
- *Risk and resilience factors*: Again Evie ticks a few boxes: a significant life event, family breakdown, that we know of. Her sport is a skill so one would hope this would act as a resilience factor, but it can also become a risk factor for Evie in combination with other features.
- *4 Ps model*: *Pre-disposing*: Earlier adverse experience and trauma of parental separation and Evie is within the age range of potential onset. *Precipitating*: there could be a recent event such as increased academic pressure, bullying, a family bereavement. *Protective*: close family unit with a caring mum and her brother, her sports talents. *Perpetuating*: potentially her ongoing sports if it becomes more demanding and competitive. Evie and her mum may deny there is a potential problem (there may not be).

The practice nurse role in both identifying young people presenting with symptoms and ongoing work

With the average length of illness being five years and inpatient stays being on average a year, it is likely a practice nurse will become involved in care and work alongside specialist teams at various points. Practice nurses are in good positions within their primary care settings to work with Tier 3 (community teams) and Tier 4 (inpatient) CAMHS. Recognition of early signs and symptoms and referral as stated above is important. If a young person was being managed in a community setting in conjunction with CAMHS, practice nurses can often contribute to care by regularly supporting and monitoring risk together with monitoring other physical signs such as the young person's weight and blood pressure. During the current pandemic much of the previous face to face consultation will now have moved to an online presence, with accompanying pros and cons.

Inpatient units are a specialised centralised regional provision around the country so often young people requiring admission can find themselves a long way from home if a local regional bed is not available. Other research has demonstrated that anorexic young people can be effectively treated and restored to a safe weight in Tier 3 provision if this is a 'day hospital' type setting. There are mixed reports about the effectiveness of inpatient versus outpatient treatment in the longer term, with inpatient treatment not necessarily more effective, unless it is for an emergency (Meads et al 2001). A study trial called 'TOuCAN'; of adolescents with anorexia nervosa (Gowers et al 2010) found little support for long in-patient stays on clinical or health economic grounds. There also tends to be quite a mix and variation in provision from the NHS and the independent sector.

Re-feeding to reverse starvation and ultimately the effects of brain starvation must commence first before an individual can enter 'therapy', although of course professionals adopt a warm and caring position and will always foster a therapeutic relationship. Behavioural and family approaches such as the *Maudsley Approach* (Le Grange and Lock, 2014) are often adopted when re-feeding. During this period there is opportunity to develop a therapeutic alliance with not only the individual but also the family members. Systemic interventions mean an inclusion of not only the child or young person but the family system around them who should also be viewed as a resource for support. Practice nurses can find themselves in the position of supporting the family especially during an inpatient stay.

Longer term approaches in the treatment of eating disorders include Anorexia Nervosa focused Family Therapy (FT-AN) and individual work including Cognitive Behavioural

Therapy (CBT-ED) and/or Adolescent focused Psychotherapy (AFP-AN), as recommended by NICE (2017).

Conclusion

Practice nurses are often seen as less intimidating than mental health professionals given the stigma attached to mental health. There are also ongoing opportunities for practice nurses to become more knowledgeable about eating disorders given the large populations that their general practices serve.

Useful websites/resources:

Association for Child and Adolescent Mental Health: <https://www.acamh.org/>

Beat: Beating eating disorders: <http://www.b-eat.co.uk/>

Eating Disorders Patients, Families and Doctors talk about the road to recovery, available from: <https://www.bbc.co.uk/sounds/play/b08wmk25> (39.08 mins, start 7.25 mins in) (accessed August 2020)

MindEd: contains a wealth of information for anybody working with children and young people's mental health issues: <https://www.minded.org.uk/>

Nadine Burke Harris TED talk (16.02 mins) *How childhood trauma affects health across a lifetime*, available from:

https://www.ted.com/talks/nadine_burke_harris_how_childhood_trauma_affects_health_across_a_lifetime

Royal College of Paediatrics and Child Health: <https://www.rcpch.ac.uk/>

Royal College of Psychiatrists: <https://www.rcpsych.ac.uk/>

Young Minds: The voice for children and young people's emotional health and well-being: <http://www.youngminds.org.uk/>

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Key points:

- Anorexia nervosa and other eating disorders cross all cultural and social backgrounds

- Anorexia nervosa has the highest death rate of any mental illness
- The risk of onset is highest between ages 13–17 years
- There is an ongoing role for practice nurses in early identification and supporting children, young people and the family together with CAMHS and school nurses
- Eating disorders arise from a combination of factors, not a single cause or source

CPD reflective practice:

- Can you consider the 4 Ps model and incorporate it into your work with your patients, not only in assisting with understanding how eating disorders emerge, but other emotional and psychological presentations?
- How do you plan to use the information in this article to inform your practice with both colleagues and your patients?
- When considering children and young people with eating disorders and working with them and their families, what plans can you make to ensure you are included as a significant professional in the team around the child or young person?

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