WHO IS THIS TOOLKIT FOR?

This toolkit is intended for use by Registered Nurses/Midwives and Specialist Community Public Health Nurses. Those providing support to children and young people who may be experiencing an eating disorder must ensure that they have an adequate level of training and understanding prior to doing so. Nurses will require access to clinical and safeguarding supervision to ensure that they are well supported when delivering any kind of intervention and to reflect upon whether they are working within their level of skill and competence. However, it is recognised that some of the information in this toolkit may also be of use to schools, parents / carers and other professionals. This toolkit has been co-produced with experts by experience, families and a group of School Nursing and eating disorder specialists.
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WHAT ARE EATING DISORDERS?

Eating disorders are biologically based, serious mental illnesses and are fully treatable with a combination of nutritional, medical, and therapeutic support - the sooner someone gets the treatment they need, the better the chance of a good recovery. They are NOT choices, passing fads or phases.

Eating disorders can be severe, fatal and can be recognised by a persistent pattern of behaviours that can cause health problems and/or emotional and social distress. Eating disorders are characterised by a persistent disturbance of eating or eating related behaviour that results in the altered consumption or absorption of food which significantly impairs physical health or psychosocial functioning.

Eating disorders include Anorexia Nervosa (AN), Bulimia Nervosa (BN), Binge Eating Disorder (BED), Avoidant/Restrictive Food Intake Disorder (ARFID), and Other Specified Feeding or Eating Disorder (OSFED).

Eating disorders are often hidden due to intense shame, guilt, and stigma. Even if a child or young person does not meet the formal criteria for an eating disorder, they may be experiencing unhealthy eating behaviours that cause substantial distress and may be damaging to both physical and psychological health. If a child or young person has been diagnosed officially with an eating disorder, or if they have the symptoms of more than one eating disorder or of disordered eating, it is important that they get the help they need to develop a healthy relationship with food.

HOW DO YOU KNOW IF IT IS AN EATING DISORDER

Does the child or young person worry about their weight and shape? Does this have a significant impact on their life? Do they demonstrate a constant pre-occupation with their body image, or a compulsive urge to body check frequently?

Do they try to control their weight by:

- Restricting their diet, avoiding ‘fattening foods’
- Do they get anxious about their food routine especially when things change?
- Do they have a compulsion to exercise?
- Do they find it hard to have a rest day from exercise?
- Do they exercise to compensate for food?
- Are they making themselves vomit?
- Do they use laxatives or medication/drugs to lose weight?
- Do they feel out of control with their eating and can’t stop and eating large amounts?
- Are they consuming large quantities of food at one time with a sense of having no control?
- Do they eat in secret, and feel ashamed about their eating?

If any of the above are answered with a yes, we would encourage a conversation about next steps with the child or young person.
1. Many people with eating disorders look healthy yet may be extremely ill.

2. Families are not to blame and can be the patients’ and providers’ best allies in treatment.

3. An eating disorder diagnosis is a health crisis that disrupts personal and family functioning.

4. Eating disorders are not choices, rather they are serious biologically influenced illnesses.

5. Eating disorders affect people of all genders, ages, races, ethnicities, body shapes and weights, sexual orientations, and socioeconomic status.

6. Eating disorders carry an increased risk for both suicide and medical complications.

7. Genes and environment play important roles in the development of eating disorders.

8. Genes alone do not predict who will develop eating disorders.

9. Full recovery from an eating disorder is possible; early detection and intervention are important.

CONFIDENTIALITY

Conversations between nurses and young people aged 12 years and over are confidential. This means that no information will be shared with school or others without permission. The only occasion where a nurse might consider passing on confidential information without consent would be to protect the young person or someone else from serious harm. Conversations with children aged 11 and younger should be shared with parent/carer.

Nurses will always encourage child or young person to inform and involve parents/carers and school as much as possible. Nurses can talk to trusted adults on behalf of those they support or can help to facilitate those conversations. Conversations and plans will be documented and stored on a health record which may, at times, be viewed by other healthcare professionals who all share the same confidentiality rules.

CONSENT

For children under the age of 11, consent should be sought from the parent/carer prior to any further conversations with the child taking place.

Young people over the age of 12 can request confidential support from a School Nursing service if they are assessed as having enough competence and understanding to fully appreciate what is involved in their support plan. This is known as Gillick competence. It is, however, always best practice to involve the child or young person’s parent/carer where possible (NSPCC, 2022).

People aged 16 or over are entitled to consent to their own treatment. This can only be overruled in exceptional circumstances. However, it is important that young people with suspected eating disorders have appropriate support available at home as well as their educational and social environments.
HOW TO SPEAK TO A CHILD OR YOUNG PERSON WHO IS STRUGGLING

• **Remember** the eating disorder isn’t about the food or body image, rather, because something else is going on for them.

• **It is important** to show that you are listening and believe/value what the child/young person who is experiencing the illness is telling you. This will help to validate their feelings, and know they are deserving of support.

• **Show empathy, compassion, and respect.** Reassure them that they are not to blame.

• **Ask open ended questions** such as: How are you feeling?”, “I’m here to listen, what’s on your mind?”

• **Allow time** for the young person to answer without interrupting (NSPCC, 2022)

• **Listen carefully and accept** what is said in a non-judgmental manner.

• **Be honest** about your understanding. Use mirroring and reflection (Royal College of Nursing, 2019).

• **Use affirmations** - “Recovery can be difficult, and this will be a challenge, but things can get better with support”

• **Empower and promote self-efficacy** “What would help you?”

• **Always have signposting information available.**

WHAT TO DO IF A CHILD OR YOUNG PERSON UNABLE TO OPEN UP

• Encourage them to speak to someone they trust.

• Signpost them to information on eating disorders.

• Remember that the eating disorder is not about the food, body image, weight, rather it is a symptom that something else is going on.

• Unless there is an immediate risk, check in with them a few weeks later asking how they are.

• If you are worried, speak to others in their support network and seek supervision and advice.

• Be patient and gentle.

• It is alright to check in with a child or young person more than once, they may not feel comfortable to open up about their feelings the first time.

WHAT NOT TO SAY TO SOMEONE WITH AN EATING DISORDER

• “Didn’t you just eat?”

• Comments around specific foods or food types, demonising them and encouraging restriction around certain foods.

• Comments on body image - “You lost weight, you look great!”

• “You weigh very little; you can afford to eat more.”

• “You should eat this, not that.”

• “It must be due to the way things are at home”
HOW TO SPEAK TO PARENTS/CARERS IF YOU HAVE CONCERNS

Show empathy, compassion, and respect. Reassure parent/carer and families that they are not to blame, and they are not alone.

Active listening. Anticipate that there may be highly emotional responses and reassure that this is a safe place to explore feelings they have at this time.

Be aware that family members may experience severe distress and may themselves require signposting to support services and acknowledge that this will impact the wider family significantly.

Allow time for families to process information that you are providing them. Check their understanding of what you have explained and ensure you provide information in a format that is easy for them to access and interpret.

Use affirmations and empower – ‘Things can change, and recovery is possible with support’ (Hope Virgo).

Consider whether there is anything else you could recommend. Can you signpost to local and national support services that would be helpful?

GP / Local support groups / podcasts
First Steps: www.firststepsed.co.uk
F.E.A.S.T: www.feast-ed.org
Shout: www.giveusashout.org
Talk ED: www.talk-ed.org.uk
Hub of Hope: www.hubofhope.co.uk
Mind: www.mind.org.uk
Mind and Soul Foundation: www.mindandsoulfoundation.org
BEAT: www.battleatingdisorders.org.uk
Samaritans: www.samaritans.org
The Mix: www.themix.org.uk
PAPYRUS UK: www.papryrus-uk.org

For more training on eating disorders please contact info@saphna.co @hopevirgo_

SUGGESTED CONVERSATION STARTERS/PHRASES

I understand how much of a shock this is.

We’ve noticed some changes with your child that seem out of character. We wondered if you had noticed anything or had any concerns yourself?

This is not your fault.

You have not failed as a parent / carer.

One of the most powerful things you can do is continue to show love for the person suffering, no matter how the eating disorder may make them behave. Remember your loved one is in there.

Meals and snacks are the way to fix the issue of being underweight; recognise how challenging that may be to achieve and empower the carer to keep going with it.

“How are you? Is there anything I can help you with?”

Explain to families that recovery is possible with support.
TAKING ACTION

If an eating disorder is suspected, refer immediately to a community-based, age-appropriate eating disorder service for assessment or treatment (National Institute for Health and Care Excellence, 2017).

Acknowledge that School Nursing services are not experts in eating disorders.

Nurses may need clinical and/or safeguarding supervision to support their decision making. Nurses should work within their scope of practice to ensure the safety of the child or young person. Carefully consider what professional support you might need to put in place now. Also consider what support may be available to the family, siblings and friends of the person affected.

Document clearly and use the voice of the child or young person. Think family, developing a person-centered and collaborative approach to planning and decision making (NHS Safeguarding, 2022).

Share information on a need-to-know basis. Ensure you let the child or young person or parent/carer know what information needs to be shared and with whom. Where possible, agree this mutually and demonstrate whether you have consent from all parties in your referral for specialist support.

When seeking consent to refer a child or young person under 16 to specialist services, respect Gillick competence if they consent and do not want their parent/carer or family members involved (Department of Health and Social Care, 2009).

IF THINGS DON’T GO SMOOTHLY

Although School Nursing services promote collaborative working with children and young people, and families, it is important to recognize that this process is not always smooth. There may be times when a child or young person or their parent/carer are not recognising your concerns, they may minimise your views and even decline consent for a referral to a specialist service.

Maintain communication with the child or young person and family. Recognise that this may have come as a shock, they may feel stigma, blame, and they may not be acting rationally.

Acknowledge that the need to share necessary information may sometimes result in loss of trust. However, this must happen if there is a risk of significant harm to the child or young person. Nurses must preserve safety in line with the NMC Code (The Nursing and Midwifery Council, 2018) and take all reasonable steps to protect those who may be vulnerable or at risk of harm. Be alert to signs of bullying, abuse, or neglect. Follow local safeguarding procedures to formally refer and escalate concerns. (Department for Education, 2018).

In these circumstances it is important to be open and honest with the parent/carer about your reasons for wanting to refer. Inform the parent/carer of your next steps: Seeking support from a clinical and/or safeguarding supervisor and inform them that you will agree a plan with them following these discussions.

Nurses should not be alone in this process. In line with their NMC code of conduct (2018), recognising and working within the limits of own competence is paramount. Ask for support, your line manager has a duty to support you to navigate scenarios such as this, will support you to make a safe decision in the best interest of the child or young person. School Nursing services may also be able to seek advice from the local eating disorder service.

With parent/carer or children and young people consent, you may wish to seek support from the GP. In some circumstances you may need to consider referral directly to A&E or paediatrics depending on the local referral pathway.
REFERRALS; TO WEIGH OR NOT TO WEIGH?

Weighing a child or young person as part of this Nursing assessment is not universally recommended. If another service requests or a referral form requires measurements for BMI, question the rationale and consider whether this is essential. You can choose to omit measurements in a referral but ensure that you provide the rationale for doing so. If it is deemed necessary, carefully consider the privacy of the environment that the height and weight assessment is conducted in.

When possible, set up weighing and measuring equipment in a separate room to encourage engagement. Prior to taking measurements ask whether the child or young person wants to know the results. Observe their wishes. Allow blind weighing: stepping backwards onto scales if this makes them feel more comfortable.

Referral processes vary across the UK. National Institute for Health and Care Excellence (2017) recommend that single measures such as BMI should not be used to determine whether to offer treatment for an eating disorder.

NICE GUIDANCE

‘Eating disorders: recognition and treatment’ (National Institute for Health and Care Excellence, 2017) suggests the following indicators may indicate an eating disorder. These points may provide some useful context for your referral. Make the referral person centered, talk about the impact on wider family and use the child or young person’s voice wherever possible.

• An unusually high or low body mass index (BMI) or body weight for their age.
• Rapid weight loss.
• Dieting or restrictive eating practices (such as dieting when they are underweight) that are worrying them, their family members or carers, or professionals.
• Family members or carers report a change in eating behaviour.
• Social withdrawal, particularly from situations that involve food.
• Other mental health problems.
• A disproportionate concern about their weight or shape (for example, concerns about weight gain as a side effect of contraceptive medication).
• Problems managing a chronic illness that affects diet, such as diabetes or coeliac disease.
• Over exercise.
• Menstrual or other endocrine disturbances, or unexplained gastrointestinal symptoms.
• Physical signs of malnutrition, including poor circulation, dizziness, palpitations, fainting or pallor.
• Compensatory behaviours, including laxative or diet pill misuse, vomiting or excessive exercise.
• Abdominal pain that is associated with vomiting or restrictions in diet, and that cannot be fully explained by a medical condition.
• Unexplained hypoglycaemia.
• Atypical dental wear (such as erosion).
• Whether they take part in activities associated with a high risk of eating disorders (for example, professional sport, fashion, dance, or modelling).
NOW WHAT?

School Nurses are post graduate highly skilled, trained, experienced and knowledgeable practitioners and, alongside other qualified team nurses, are well placed to support children or young people experiencing an eating disorder, however, it is important to recognise that they are not specialist mental health services that many children or young people require and, as such, must not be expected to nor offer to plug/substitute often extremely long waiting lists such as Child and Adolescent Mental Health Service (CAMHS). In these cases, it is paramount you escalate to your management for the development of a management plan.

As public health leaders for school aged children and young people, School Nurses can offer early identification, assessment, brief intervention, referral, signpost, and advocacy. Primary care, GP’s, mental health charities, schools’ pastoral leads, counsellors, mental health support teams and online self-help are important support options; explore what is available in your area.

Ensure you paint a realistic picture – inform families of what might happen next and how long it could take. Prepare them for what is to come. Provide ongoing support by being a listening ear; gather information and resources to share so that families can access these.

Think about recovery. Remember: physical and behavioural changes don’t equal full recovery.

A child or young person’s mental health can take longer to heal, and this should be taken into consideration when reviewing progress.

DONT FORGET

Remember to hold onto hope; recovery is always possible.

Have a plan in place for follow up – see eating disorder safety plan below or consider an emergency plan if the child or young person has expressed feelings of helplessness or suicidal thoughts (4 Mental Health, 2020).

Nobody is to blame

Demonstrate understanding – be there to listen and not judge.

Look at the WHOLE person and their support network. Who do they want to be involved? Listen to and value the voice of the child or young person.

Don’t lecture

Don’t just focus on the weight. Remember BMI is not an indicator of overall health.

Be prepared to signpost to local and national services / websites.

Be aware that offering professional support can trigger feelings and emotions which can be overwhelming. You should be able to seek support from your clinical and safeguarding supervisors. See signposting services section above for some additional places to seek support.
## MY SAFETY PLAN

We suggest this safety plan should be revisited on a monthly basis or more regularly if required. Schools can complete this with child or young person, their parent/carer and the School Nursing service may be able to support if required.

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who can I seek out as a trusted person when I need support?</td>
<td></td>
</tr>
<tr>
<td>Where is a safe space that I can access when I need to?</td>
<td></td>
</tr>
<tr>
<td>When can I access this?</td>
<td></td>
</tr>
<tr>
<td>What should I do if I am not feeling ok in a lesson / during the day?</td>
<td></td>
</tr>
<tr>
<td>Who else could I seek out if I am not feeling okay?</td>
<td></td>
</tr>
<tr>
<td>We can use the following resources for support...</td>
<td></td>
</tr>
<tr>
<td>My sibling / close friends can seek out this staff member for support.</td>
<td></td>
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<tr>
<td>My friends are aware / not aware of what is going on for me. I would / would not like support with telling them.</td>
<td></td>
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<tr>
<td>Other support I may require.</td>
<td></td>
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<tr>
<td>What have I achieved / accomplished since my safety plan was last reviewed?</td>
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</tbody>
</table>

If the child or young person has expressed helplessness or suicidal thoughts visit: [https://staying-safe.net/what-is-a-safety-plan](https://staying-safe.net/what-is-a-safety-plan) and share concerns with parent/carer and health professionals involved (4 Mental Health 2020)
REFERENCES


4 Mental Health, (2020) What is a safety plan? [online] Available at: https://www.stayingsafe.net/what_is_a_safety_plan [Accessed 3 October 2022].

Contact info@saphna.co to find out more about the training we provide.

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