



PARENT TOOLKIT

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WELCOME

Eating disorders not only affect the individual diagnosed – they also have a profound impact on their family members. Unfortunately, the effects on siblings are often overlooked, with many siblings reaching out to Eating Disorders Families Australia (EDFA).

This first-of-its-kind project seeks to support individuals aged 10-17 years who have a sibling with an eating disorder.

Capturing the far-reaching effects on siblings was important to us. To do this, EDFA conducted a co-design workshop where we gathered insights directly from siblings about their lived experiences and what they feel would have been beneficial for them. The resources in these toolkits are informed by current literature, feedback from parents on the challenges of raising multiple children during eating disorder recovery, and most importantly, the invaluable perspective of siblings.

While we acknowledge that the impact on siblings is complex and varied, we have made every effort to accurately reflect these effects on siblings.

While siblings require specialised guidance to support their emotional wellbeing, the codesign workshop demonstrated the key role that parents play in supporting the siblings' wellbeing.

To address this, we have created three distinct toolkits. The Parent Toolkit offers insight into the sibling's experience and strategies for parents to offer effective support. Building on this, the Sibling and Parent Toolkit is designed to help parent and child connect and communicate more effectively.

The Sibling Toolkit is designed for siblings to work through on their own. The toolkit offers validation for the challenges they may be experiencing and provides activities for distraction and self-care. Most importantly, it empowers siblings to identify and understand their emotions, establish healthy boundaries to protect their wellbeing, and develop coping strategies to manage concerns about their sibling's health.

While we understand that siblings may also struggle with disordered eating (or even an eating disorder), these toolkits do not address these issues due to the potential for vulnerable young people to access these resources. If parents or siblings are worried about their weight, food, or eating, seeking professional support is highly recommended.

The term parent throughout these toolkits refers to anyone caring for a child aged 10-17 who has a sibling with an eating disorder. We recognise that parents and siblings can be biological and non-biological. For anyone identifying as a parent or sibling, this resource is for you.

ACKNOWLEDGEMENTS

Eating Disorders Families Australia would like to thank the Helen and David Hains (HDHF) Foundation for the generous donation that made this project possible. We are immensely grateful to HDHF for the opportunity to support siblings through these resources.

We thank Press Room Partners for their ongoing and long-term support providing the design and printing for this project.

To the siblings who welcomed us into their world and opened up about their experience – thank you. You are wonderful, and we are honoured to be able to provide support to other siblings because of your willingness to share.

We thank Jordana Csoti, author of this project. These resources are a product of her professional expertise, and we are grateful for Jordana's knowledge and willingness to share.

Lastly, to the parents and siblings who are living through challenging times - we see you. Thank you for being here and taking the time for self-care. Remember, you matter too.

FEEDBACK

We welcome feedback on our services, particularly new projects. If you'd like to provide feedback, please email feedback@edfa.org.au.

DISCLAIMER

This document is not a substitute for independent professional advice and EDFA strongly recommends that users obtain any appropriate professional advice relevant to their particular circumstances. Never disregard professional mental health or medical advice or delay in seeking treatment because of something you have seen in this document. You must make your own assessment of the information contained in this document and, if you choose to rely on it, it is wholly at your own risk. No person should act or fail to act on the basis of these materials.

EDFA does not recommend or endorse any specific treatments, therapies, medications, clinicians or healthcare providers. The content in this document is meant for educational and informational purposes only and does not constitute a recommendation for any particular course of treatment. Any decision should be made in consultation with a qualified mental health professional or medical practitioner.

This document may also include links to other websites. These links are provided for your convenience to provide further information. They do not signify that EDFA endorses these other website(s). EDFA has no responsibility for the content of the linked website(s). It is the responsibility of the user to be aware of which organisation is hosting the website they are visiting and to make their own decisions about the accuracy, currency, reliability and correctness of information contained in that linked site.

SUPPORTING SIBLINGS: HOW CAN PARENTS HELP?

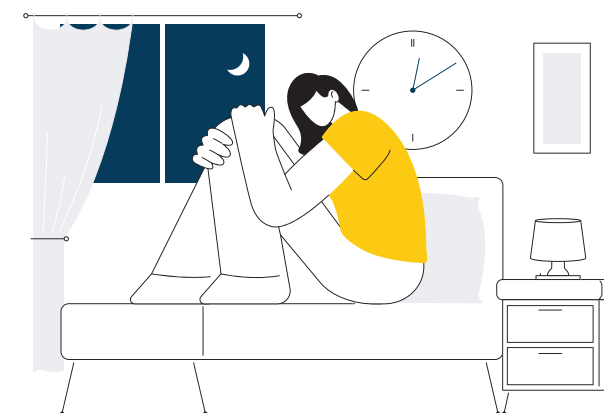
Navigating an eating disorder diagnosis in the family is difficult and often has an impact on all members of the family, particularly when there are multiple children in the home. It's certainly not easy balancing all your children's needs!

Families in the EDFA community have shared their strategies on what has helped them simultaneously support their child with an eating disorder, as well as their other children.

WHAT MIGHT MY CHILD BE FEELING?

Each young person's experience of being a sibling to a child with an eating disorder diagnosis will be different. However, there are some common experiences that research and lived experience highlight. Understanding the sibling's experience is a good way to help minimise the impact of the eating disorder and maintain the sibling's well-being.

- Siblings may feel as though their own life has been disrupted - that the family they knew and loved has changed without their permission. This can cause some siblings to feel a sense of loss and confusion, grief, and perhaps even anger.
- Siblings can feel as though their role within the family has changed. This means that they might feel as though their parents are less available than they used to be, or that the sibling dynamic has changed. Some siblings have reported that they felt as though they went from being a younger sibling to playing the role of the more responsible, independent, oldest child. This can be particularly jarring if they are the youngest in the family and not equipped for the additional responsibility (such as supervising meals during refeeding).
- Siblings may not want to burden their parents with their own challenges, so as not to add to their parents' stress. Siblings may also feel as though they need to be a support to their parents during recovery.
- Some siblings may feel as though they now come second to their unwell sister or brother. It can feel as though family members, friends, and clinicians prioritise the unwell sibling, even when they have their own challenges for which they need support. While this is understandable, it can sometimes feel as though conversations are monopolised by the eating disorder and that they themselves have become less important.
- Some siblings may not understand eating disorders. Given eating disorders can be difficult for even adults to understand, siblings may be struggling to understand what an eating disorder is and why their brother or sister is acting in the way they are. This can sometimes lead to strong feelings ranging from confusion, to resentment and hatred. It can be heartbreaking to see one child feel so negatively towards another, but understanding it is a common experience can help alleviate some of the distress parents can face in these situations.
- The relationship between siblings and their unwell brother and sister can become strained or different from the way it used to be. For some siblings, this can generate feelings of loss or sadness.



WHAT CAN I DO TO HELP?

Each sibling will respond in different ways to the changes resulting from the eating disorder entering their family. Below are examples of things parents can do to help support the siblings in the family. It may be worth experimenting with different approaches and seeing what works for you, the sibling, and your family.

It's important that parents try other methods if the first isn't effective. Don't give up trying to support the sibling. While it can be disheartening when you don't feel as though your efforts are being recognised, you never know the impact of simply showing up. People want to feel seen, and by making an effort, you are sending the message that your other child is important too.



- Where possible, try and stick to your regular daily routine, particularly regarding things that are important to the sibling, such as sporting or other extracurricular activities. This might mean that you need to call on a friend to take them to or from their commitments, but it's important that, where possible, they maintain stability.
- Talk to the sibling about the idea of individual therapy for themselves through either EDFA, other support services, or a private clinician.
- Some siblings have found that notifying their school about what is going on in the family can be helpful. This can allow siblings to receive emotional support via check-ins and school well-being services but also gain leniency and understanding with schoolwork pressures. Having teachers at school who know what's going on means the sibling has additional adults they can turn to.
- Ensuring the sibling has time away from the family unit can be helpful. Some siblings have noted that having a few close friends whose parents know what is going on has helped them gain extra support and understanding. This also provides siblings with a safe, loving place to be when they need time away from the family home.
- If there is a family member the sibling has a strong relationship with (such as aunt or uncle), try and encourage these connections during these more stressful times.
- It's important for siblings to feel comfortable seeking out their parents for assistance in the struggles they face navigating adolescence, independent of their sibling's eating disorder. Checking in with the sibling regularly provides them with the opportunity to talk about what's going on without having to seek you out. Our Parent & Sibling Toolkit can help you communicate with the sibling.
- Spend intentional time with the sibling doing things that they enjoy. This can be beneficial in two ways: it can help reiterate their importance in your life, as well as give them time and space away from the eating disorder and their sibling. It might mean getting someone else to stay with your child who is unwell while you and your other kids have fun. It's helpful to do creative activities around food, so they can see they can get attention from each parent without needing to resort to unhealthy behaviours. It can also help model a normal, fun relationship with food.
- Maintaining an open dialogue about what's going on within the family regarding their sibling's eating disorder treatment is important. Helping a sibling understand more about how eating disorders can operate is a good way to not only improve their understanding of what's going on within the family but also better understand their sibling's experience. This might look like explaining that an eating disorder is an illness that may sometimes control their sibling's words and behaviours, but the sibling they used to know is still there and can come out again.
- Where possible, include the sibling so that they feel as though they are an important part of the family. For example, if the child with an eating disorder plays games such as Bananagrams around mealtimes for distraction, ask the sibling if they would like to join.
- Some siblings may deal with things by talking to their friends, or by distracting themselves – not all siblings will want professional help. While it is important to keep the dialogue around this open, it's also important to not push them too hard; every young person will manage themselves differently.
- Divide and conquer! Some parents have found it works best when one parent takes the lead on supporting the child with the eating disorder, while the other parent (or even close family relative) takes the lead on supporting the sibling. This can help both children feel as though they have consistent support and someone backing them at all times.



DIFFICULT CHOICES

Unfortunately, there are going to be times when you have to make difficult choices. In extreme cases, you may be required to choose between which of your children to support. For example, do you stay with your child who is hospitalised due to their eating disorder, or do you celebrate your other child's birthday? In the same way that you may have to prioritise the unwell child at times, there will be times when it's important to prioritise the sibling.

You may not expect it, but it can have a positive impact on your child who is unwell. One carer shared that this was a pivotal moment for her daughter, as she realised her mum wasn't going to be there at all times, even when she was in hospital. It helped her realise that she is responsible for her own recovery.

REMIND THEM IT'S NOT THEIR ROLE TO FIX THEIR SIBLING

While siblings may often be involved in Family Based Therapy (FBT) and may want to help their brother or sister, it is important to remind them that it's not their role to be the carer. The parents are responsible for their care, and siblings have permission to be a child, including having fun with their friends and maintaining as much of their childhood as possible.

Remind them that you are there for them, their feelings are important and valid, and that you will help them navigate this challenging experience.

LOOK AFTER YOURSELF

It is important to remember that things are a little different than they used to be and that you may not be able to be there for the siblings as much as in the past, but you are doing the best you can in a challenging time. It is common for the siblings to experience their own challenges during recovery, however it is not your fault.

Continue to reach out to those around you for support and encourage your child to seek their own support.



NEW FAMILY TRADITIONS

When a child is diagnosed with an eating disorder, life often changes – at least temporarily. One of the most noticeable shifts is how much family traditions, social activities, and quality time tend to revolve around food. As a result, it's important to find new ways to spend time together and enjoy each other's company without focusing solely on food. It is also a time when things that bring the family together are more important than ever.



Celebrating milestones, such as birthdays, may require some adjustments. Instead of a large family dinner, consider a one-on-one celebration with each child, where they can enjoy a special or adventurous meal with their parent(s). This way, they can focus on having a good time without the added stress of worrying about how their unwell sibling might react to the situation.



Holidays can be adapted to make them more inclusive and ensure that the family is still able to spend quality time together. It's important not to completely remove food from these celebrations, as eating together remains significant for the well members of the family and helps reinforce the normalcy of eating for the child struggling with an eating disorder. However, incorporating other activities can help shift the focus away from food and reduce stress.



Weekly family TV time can provide a regular opportunity for everyone to come together. Though it might not always seem like 'quality time', watching a show as a family can take everyone's mind off the eating disorder and give the family something to talk about and look forward. If there's nothing exciting on free-to-air TV, try an online streaming series. Depending on your family's age group, consider shows like The Block, Friends, Gilmore Girls, Malcolm in the Middle, Brooklyn 99 or Modern Family. Comedies can also help lighten the mood!



Board games and card games offer a great way to connect and have fun as a family. Classics like Monopoly, Articulate, Bananagrams, or Uno can help build memories, promote connection, communication, and healthy competition, all while strengthening family bonds. Building Lego together can also be a good idea; there are several adult sets that operate in a similar way to puzzles.



Pamper nights are an excellent way to combine self-care with family bonding. These nights emphasise the importance of looking after oneself while enjoying a light-hearted evening together. Pick up some products from the chemist, or use our simple face mask recipe (see Toolkit 3). Play music, paint nails, or help each other straighten or curl hair – these small, simple activities can turn into meaningful moments of connection.

If none of these ideas resonate with your family, that's okay – the key is to focus on what brings you together. Think about the activities that make everyone happy and start there. Whether it's watching sunset by the beach, taking the dog to the park on a Saturday morning, or something else entirely. All that is important is making a conscious effort to incorporate things that bring joy into your family life.

SUPPORTING SIBLINGS

SERVICES FOR

SIBLINGS AND PARENTS

When one person is struggling with an eating disorder, it can affect the whole family. However, recovery is possible, and there is always hope.

Carers often sacrifice their own well-being to prioritise the care of their loved one, particularly in times of financial stress or when in short supply. However, parents and siblings can benefit from support while navigating recovery. It is important to remember that seeking help for yourself and your loved ones not only supports your own well-being, but also enhances the support you can provide for your child.

While it's natural to feel overwhelmed and uncertain, you are not alone. Below you'll find a list of free support services, mostly available online, to help support you through this challenging time.



HELPLINES

There may be times when you or your young person need immediate help.

In an emergency
call emergency services on 000

If the situation is not an emergency
Lifeline – 13 11 14
Kids Helpline – 1800 551 800
Beyond Blue – 1300 224 636

SIBLINGS

The below services are available to all Australian siblings regardless of their level of involvement in treatment.

EDFA

Individual Counselling

EDFA offers individual counselling sessions for children and adolescents aged 10 - 17 with a sibling with an eating disorder. Sessions aim to provide siblings with the unique support they need during this complex time. All sessions are online, free, and 45 minutes. Referrals are not required, and there is no cap on how many sessions carers can attend. These sessions can be booked at edfa.org.au/counselling-service.

Support Groups

EDFA also offers a support group for siblings over 18. The group aims to give siblings a voice in a safe space, helping them understand their role as a sibling. Sibling support groups can be accessed at edfa.org.au/parents-and-carer-support/eating-disorder-support-groups/.

Headspace

While it is not an eating disorder-specific service, headspace is a nationwide organisation that offers support to young people aged 12-26. Services are available both online and at various locations across Australia.

School Services

Most schools have a well-being team that often includes a counsellor or psychologist. School counsellors can support young people through their experience as a sibling, provide support during difficult moments, and assist in facilitating a more supportive school experience.

PARENTS

EDFA

EDFA offers both group and individual sessions for carers of children with eating disorders.

Individual Counselling

EDFA's Fill The Gap Counselling service provides support for parents whose loved one has an eating disorder.

This is one-on-one counselling support for carers of those with any eating disorder. All counsellors have lived experience of caring for their loved one, and help by providing education and supportive counselling while carers navigate their unique situations.

All sessions are free, online and 45 minutes. Referrals are not required and there is no cap on how many sessions carers can attend. Book a session at edfa.org.au/counselling-service

Support Groups

Parents are invited to attend EDFA's Carer Support Groups, which cater to the different types of eating disorders. This allows carers to connect and learn from others navigating similar challenges, and meet others who understand.

Support groups are held for an hour and are run by facilitators with lived experience of caring for a loved one with an eating disorder. There is no expectation to share, and you are welcome to maintain anonymity. Learn more about the different Support Groups provided by EDFA, and register to attend a group at edfa.org.au/parents-and-carer-support/eating-disorder-support-groups/

Private Facebook Group

EDFA's Facebook group provides a supportive community and a safe, confidential space for parents whose child has an eating disorder. Our lived-experience moderators provide a protected space for carers to gain support, learn new ways of relating to or caring for their loved one, share knowledge and encouragement, and provide hope with stories of recovery. Details of how to join the Facebook group can be found at edfa.org.au/forum/

Butterfly Foundation

The Butterfly Foundation provides telephone and online support to those with an eating disorder, as well as their family and friends. Head to butterfly.org.au for the online chat, or call 1800 33 4673 (1800 ED HOPE).

F.E.A.S.T

The US-based organisation provide peer support, education, and empowerment for carers through free programs and services. Find more information about these services at feast-ed.org, or at info@feast-ed.org.

Eva Musby

This service offers help for children and teens with anorexia and other eating disorders. The website provides resources for carers and can be accessed at anorexiafamily.com/individual-support.

Eating Disorders Victoria

Eating Disorders Victoria offers free services for those with an eating disorder, and their family. EDV can be accessed at eatingdisorders.org.au, or on 1300 550 236.

Eating Disorders Queensland

EDQ offers free services for those with an eating disorder, and their family. EDQ can be accessed at eatingdisordersqueensland.org.au/carers-and-key-supports, at admin@edq.org.au, or on 07 3844 6055.

Carer Gateway

While it is not an eating disorder-specific service, Carer Gateway is an Australian government initiative to assist carers in improving their well-being and ability to provide care. The service can provide carers with up to six free individual counselling sessions, up to six coaching sessions, and emergency respite. Contact Carer Gateway on 1800 422 737 or via their contact form at carergateway.gov.au/about-us/contact-us.

SIBLINGS WHO DEVELOP AN EATING DISORDER

Children whose siblings have an eating disorder can often be heavily affected. Unfortunately, siblings can end up with their own challenges around food, body image, and exercise. This could be due to a number of factors, including genetics, which can make siblings more vulnerable to developing an eating disorder.

Siblings can have shared personality traits – such as perfectionism or difficulty understanding their own emotions – which can be drawn upon (often unintentionally) to manage their distress.

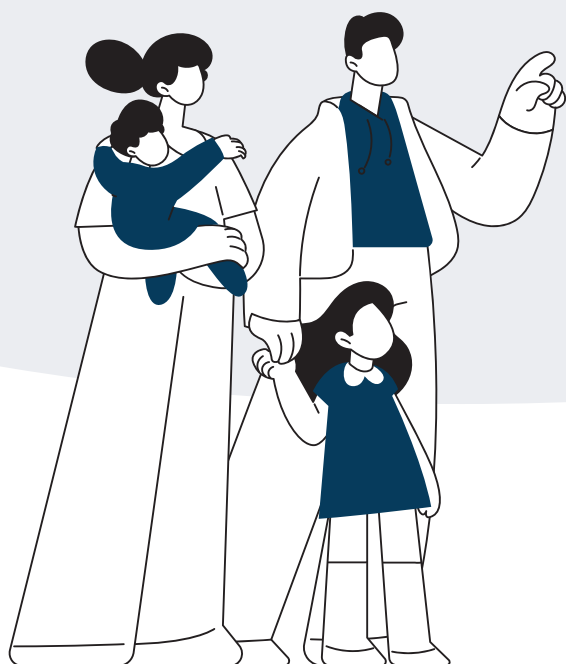
If you do decide to speak to your young person about their increased risk, it's important to be mindful of how you communicate this – particularly in terms of genetic factors. Children who experience anxiety and internalise the things they hear can interpret this genetic vulnerability to mistakenly hear that they are guaranteed to develop an eating disorder. Because of this, using age-appropriate and supportive language is key.

You may think that you can easily spot the signs, due to your experience with your other child's eating disorder. However, eating disorders can look different in each child, and therefore one child's experience doesn't predict another's. Symptoms and behaviours may show up in different ways, meaning that one child might experience a different type of eating disorder, or their signs could appear differently than in your other child.

It's also important to remember that not every child who shows signs of unhealthy thoughts and behaviours around food, body image and exercise will develop a full-blown eating disorder; they may never progress further than disordered eating.

The good news is that recognising these signs early gives your child the best chance of getting the help they need. Research shows that early support can make a big difference in recovery, leading to better outcomes for their health and emotional wellbeing. The sooner treatment begins, the better.

EDFA's Nourish, Nurture, Notice program supports carers concerned about their child's disordered eating. Access the Masterclass and drop-in session with a paediatric dietitian and mum with lived experience at edfa.org.au/nourish-nurture-notice/.



There are some common warning signs to look out for:

BEHAVIOURAL WARNING SIGNS

- Changes to eating habits such as removing food groups, opting for 'diet' or 'low-calorie' foods, suddenly becoming vegetarian/vegan, or developing an undiagnosed 'food intolerance'.
- Avoidance of eating meals, with excuses such as they have already eaten.
- Developing eating 'rituals', such as cutting food into small pieces, eating from a particular plate, or only eating at certain times.
- Hiding uneaten food, being dishonest about what they've eaten, avoiding family meals, excessive fluid intake.
- Signs of vomiting, such as frequently using the bathroom or showering shortly after meals.
- Overeating, eating at unusual times, eating alone, hiding food containers or wrappers, eating in response to emotional stress.
- Excessive exercising, exercising in secret, or exercising to compensate for eating.
- Spending excessive time cooking for others and not eating the food themselves.
- Avoiding social situations involving food.
- A change to clothing choice, such as wearing baggy or loose clothes.

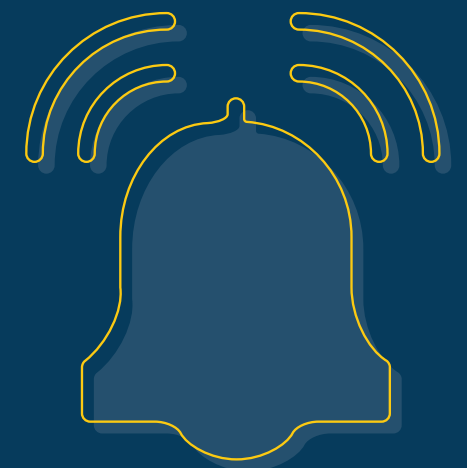
PHYSICAL WARNING SIGNS

- Significant weight changes (increase or decrease) over a matter of weeks.
- Fainting or dizziness.
- Complaining of feeling cold.
- Changes to, or lack of, menstruation (girls).
- Inability to focus or concentrate.

PSYCHOLOGICAL WARNING SIGNS

- Becoming socially isolated or withdrawn.
- Anxiety or depression.
- Inaccurate perception of body image such as feeling overweight when they are not.
- Low self-esteem.
- Perfectionism.
- Body dissatisfaction, seeking reassurance about body size, obsessively weighing themselves, and checking in the mirror.

You can learn more on the ways in which eating disorders show up via EDFA's Nourish, Nurture, Notice program at edfa.org.au/nourish-nurture-notice/.



EARLY INTERVENTION

Even if you're already supporting a child through treatment, you'll likely find that each child's needs are different. The best approach will depend on the behaviours the child is showing, how long they have been engaging in these behaviours, and the child's age. Treatment often involves a team of professionals, such as a doctor, a dietitian, and a mental health expert like a psychologist/psychiatrist. This team works together to focus on your child's overall health, eating habits, and any emotional or mental factors that might be contributing to the disorder.

INITIAL STEPS

A helpful first step is to schedule an appointment with your GP, who can assess your child's behaviours, monitor any health concerns, and refer you to specialised treatment, if appropriate. Before the appointment, it might be useful to

fill out and bring along the Feed Your Instinct eating and body image checklist, which can give your GP a clearer understanding of the situation. You can access the questionnaire at feedyourinstinct.com.au.

Keep in mind that not all GPs are well-versed in eating disorders. If you feel that your concerns are not properly addressed, don't hesitate to seek another opinion. It can be helpful to find a GP who has an interest in eating disorders or mental health. The Australia and New Zealand Academy for Eating Disorders (ANZAED) (connected.anzaed.org.au) and the Inside Out Institute (insideoutinstitute.org.au) offer resources to help you find specialised professionals. Because eating disorders can be complex, family members and carers play a very important role in supporting their loved one throughout recovery, and advocating for their loved one's care.

THE NEXT STEPS

ACUTE CARE

If you notice any symptoms (psychological or physical) that require urgent care and they cannot be seen immediately by their GP, then a hospital emergency department is the appropriate next step.

ACCESSING SPECIALISED CARE

Specialised psychologists and dietitians can also be found using the ANZAED and Inside Out tools. If your child meets the necessary criteria, the Medicare Eating Disorder Plan offers access to up to 40 sessions with a psychologist and 20 sessions with a dietitian. Specialised free treatment may also be available through the Child and Adolescent Mental Health Services (CAHMS) or Child and Youth Mental Health Services (CYMHS), depending on your location.

DISORDERED EATING BUT NO DIAGNOSIS

Sometimes, a sibling may show signs of disordered eating but not meet the full criteria for a diagnosis. You can still be a support to your loved one without a diagnosis. Even in these cases, it is important to intervene early to help stabilise things and prevent the development of an eating disorder. In these circumstances, it can be beneficial to speak to a GP.

You can also access EDFA's Nourish, Nurture, Notice program, which supports carers concerned about their child's disordered eating. Access the Masterclass and drop-in session with a paediatric dietitian and mum with lived experience at edfa.org.au/nourish-nurture-notice/.

While this means your child may not be eligible for a Medicare Eating Disorder Plan, they may still be eligible for a Medicare Mental Health Care plan which offers 10 rebated sessions with a private psychologist. Alternatively, services such as Headspace can offer low-cost psychological care.

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