

Empowering caregivers with strategies to support children with symptoms of Avoidant/Restrictive Food Intake Disorder (ARFID)

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January 22, 2025

Welcome! We will begin the presentation shortly.
Please note that your microphones have been muted and your cameras are turned off.

1



Kelty Mental Health Resource Centre

We help families across the province by:

- Helping with understanding and navigating the mental health system
- Listening and offering peer support, and
- Connecting families to resources and tools



2

Housekeeping

- Attendees are automatically muted and their cameras are turned off.
- We will answer questions that were sent to us in advance.
- Please submit questions for the speakers using the “Q&A” function.
- Please submit technical questions and comments using the “Chat” function.
- We will invite you to complete a survey after the webinar. It will pop up in your browser.
- The webinar will be recorded and shared on KeltyMentalHealth.ca/Events
- The information in this webinar is specific to British Columbia. If you are joining from another area, please contact your local health authorities for further information.

3



Speakers




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4

Disclosures 

- Jennifer Coelho receives research funding from:



Provincial Health Services Authority
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SSHRC CRSH


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Canadian Institutes of Health Research / Institut de recherche en santé du Canada

Michael Smith Health Research BC


BC Children's Hospital
Research Institute

THE UNIVERSITY OF BRITISH COLUMBIA
BC Eating Disorders Research Excellence Cluster

5

Disclosures 

- Katelyn Boerner has a small private practice and receives research funding from:



CIHR IRSC
Canadian Institutes of Health Research / Institut de recherche en santé du Canada

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6



7

Grounding Ourselves in Eating Disorder Truths

Nine Truths about Eating Disorders

TRUTHS

- 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, but serious biologically influenced illnesses.
- 5 Eating disorders affect people of all genders, ages, races, ethnicities, body shapes and weights, sexual orientations, and socioeconomic statuses.
- 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.

Academy for Eating Disorders® | www.aedweb.org

Produced in collaboration with Dr. Cynthia Bulik, PhD, FRED, who serves as distinguished Professor of Eating Disorders in the School of Medicine at the University of North Carolina at Chapel Hill and Professor of Medical Epidemiology and Biostatistics at the Karolinska Institute in Stockholm, Sweden. "Nine Truths" is based on Dr. Bulik's 2014 "Eating Disorders Myths Buster" talk at the National Institute of Mental Health Alliance for Research Progress meeting. Leading associations in the field of eating disorders also contributed their valuable input.

The Academy for Eating Disorders® along with other major eating disorder organizations (Families Empowered and Supporting Treatment of Eating Disorders, National Association of Anorexia Nervosa and Associated Disorders, National Eating Disorders Association, The International Association of Eating Disorders Professionals Foundation, Residential Eating Disorders Consortium, Eating Disorders Coalition for Research, Policy & Action, M&B Service Eating Disorders Association, Single Eating Disorder Association, Eating Disorder Parent Support Group, International Eating Disorder Action, Project HEAL, and Trans Pops Fighting Eating Disorders, and other organizations) will be disseminating this document.


8

Learning Goals

Identify what eating patterns may be ARFID


Learn ideas for making changes to eating routines

Understand how to support your child if their eating is connected to another concern (like pain)



9

Adrian's Story

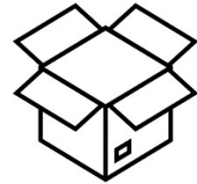


10

Your child may be living with ARFID if they are not eating enough and they:



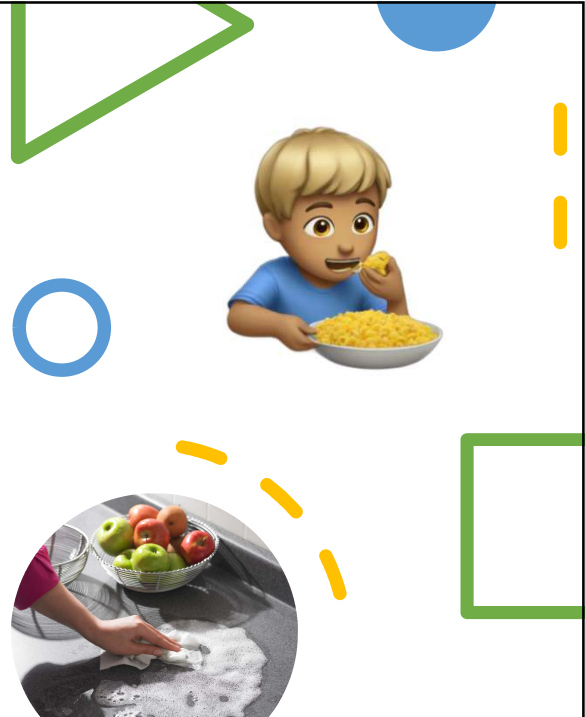
- > Do not grow as expected
- > Lose significant weight
- > Experience nutritional deficiency
- > Need to have tube feeds
- > Only drink oral supplements or meal replacement
- > Have a hard time socially, because of their eating



11

If your child has another condition or diagnosis:

- > Is their eating problem more severe than what is expected for that condition or diagnosis?
- > Does your child need medical help for their eating problem?



12

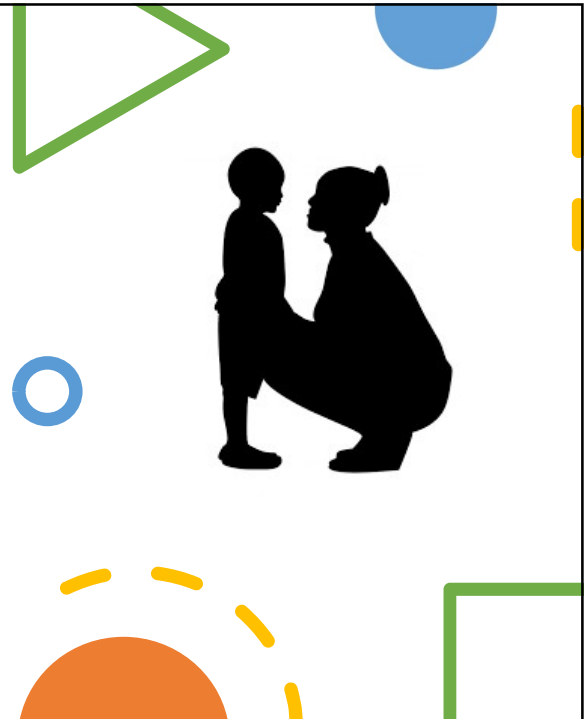
Assessment Tool

- <https://nedic.ca/arfid-screen/>



13

- › **Ellyn Satter's Division of Responsibility**
 - › Parents set the expectation of what, when, and where meals will be served
 - › Children decide whether and how much to eat (Satter, 1986)
- › Families living with ARFID often share they have tried everything. Recommendations that may be useful for children without eating disturbances may not help children with ARFID.



14

Canadian Pediatric Surveillance Project on ARFID

(Katzman et al., 2021)

- › Children ages 10-14 were most likely to grow more slowly than expected, during a time that is usually an adolescent growth spurt.
- › **Approximately 40% of children with ARFID needed hospitalization.**



15

Should I worry about other eating disorders?




- › Younger children may say they are not worried about gaining weight, but not eat enough to gain weight. They may not understand that low weight is a serious health concern.
- › Younger children may not have the language to talk about their body image. They may show distress in other ways.
- › Approximately 8% of youth initially diagnosed with ARFID were later diagnosed with anorexia nervosa (Norris et al., 2020)




16

What you can do: Ideas for making changes to eating routines




When you understand what drives your child's ARFID symptoms, you can help change their eating patterns




17

What are some eating behaviours that fit with ARFID?


Fear of consequences




Sensory Sensitivity

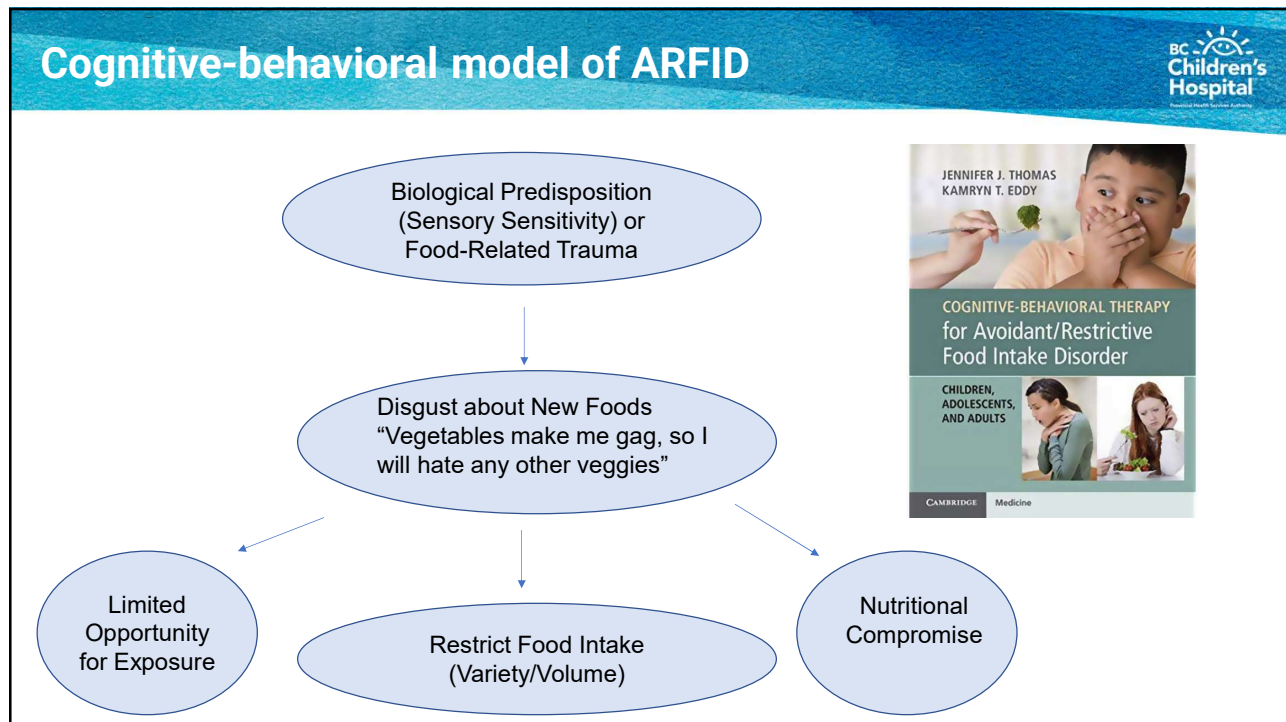


Lack of interest in eating

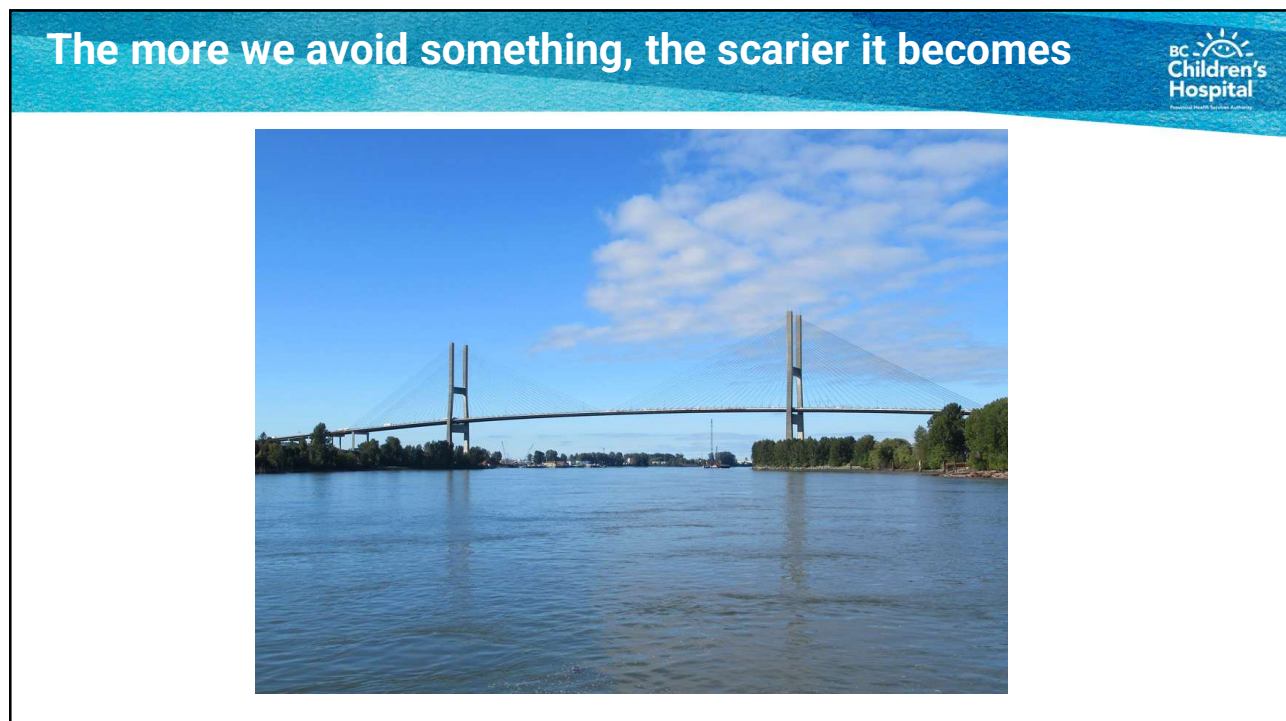




18



19




20




Strategies: When your child is not interested in food, or has sensory sensitivities

21




Strategies: Lack of interest or sensory sensitivity

Families sometimes end up with battles or meltdowns at the table. If your child is not ready for a food to be on their plate without tears or negotiations, think about starting with having the food at the table



We gratefully acknowledge:



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Strategies: Lack of interest or sensory sensitivity

Encourage positive interactions with food

- › Put produce in the basket at the supermarket
- › Help with food preparation and cooking
- › Crafts or play incorporating foods



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Strategies: Lack of interest or sensory sensitivity

Consider nutrition
over several days
(or even a week)

- Not every meal needs to be balanced
- If your child avoids one or more food groups completely, a dietitian can help
 - In BC: You can call 811 to get started

Earlier
intervention is
helpful

- We hear from families that they wait to get help because people tell them that this is a phase, and that their child will grow out of it

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Reframing 'health' messages



25



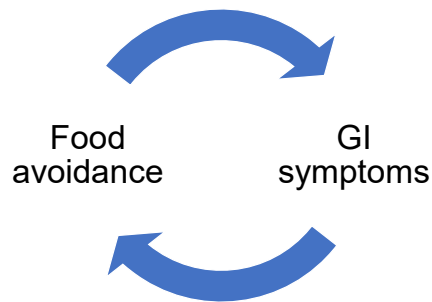
When eating
problems go
together with other
concerns, like pain



26

ARFID with physical symptom concerns

Worries about negative consequences of eating is often linked to physical symptoms like abdominal pain, difficulty swallowing, nausea, bloating and vomiting.



27

ARFID with physical symptom concerns

- › Manage any medical conditions
 - › A team can help: consider mind, movement* and medicine
- › Know what foods to avoid (because of allergies, for example)
- › Break the avoidance cycle through exposure
 - › Mechanical eating: Eat by the clock, not by the symptom
- › Develop coping strategies to reduce and manage symptoms. Focus on improving FUNCTION (what matters to you!)
- › Get supports for other areas, if your family needs them (for example, school, sleep, mental health)

28

Resources to help with physical symptoms

- > Guided imagery, relaxation, and self-hypnosis for gastrointestinal symptoms
 - > <https://imaginaction.stanford.edu/>
 - > www.thecomfortability.com
- > General resources
 - > <https://gikids.org/> (for families)

29


Family experiences

- Interviews with 6 families of children aged 8-14 years diagnosed with ARFID and/or a GI-related SSRD who received care at BC Children's Hospital
- Findings help us to understand how to support families

Young, Boerner, Marshall, Dhariwal, & Coelho (2024), *Cognitive and Behavioral Practice*

30

Common themes in family care journeys



Drifting aimlessly: Managing uncertainty in diagnosis and treatment

Emotional impact on families

Systemic barriers to accessing and implementing treatment

"Well, of course you feel um, you feel frustrated and [pause] you know, you feel like your doctor is dismissing your concerns."

"...the sense I'm getting is that, you know, they're still developing the expertise, let's say, um in house on ARFID."

"...I feel like all the process starts, but it never gets followed through."

"It was just hard. I feel lonely in my journey with my child."

"I felt helpless. I felt like I was—you know, fighting for somebody to hear him. ... Um, like, you know, you feel guilty..."


"...I also feel like um, we don't really have the resources here for people to actually help him."

"If treatment is generic, this is not necessarily going to help. ...'Cause it doesn't seem like they're really thinking specifically about your child and her needs."

Young, Boerner, Marshall, Dhariwal, & Coelho (2024), *Cognitive and Behavioral Practice*

31

Learning from family care journeys



Identifying a pathway

Support for families

Reducing barriers

- Regular medical monitoring

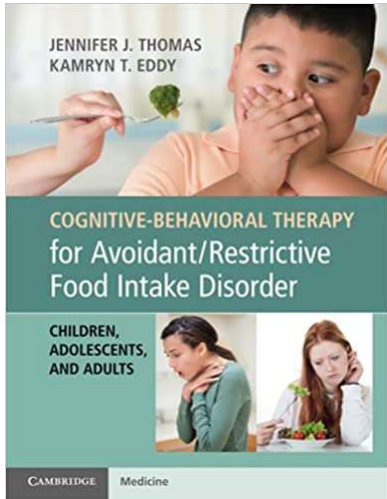
- Resources available
- Peer support

- Connecting care team members with each other

Young, Boerner, Marshall, Dhariwal, & Coelho (2024), *Cognitive and Behavioral Practice*

32

Options for Treatment/Support: CBT-AR



From childhood through adulthood

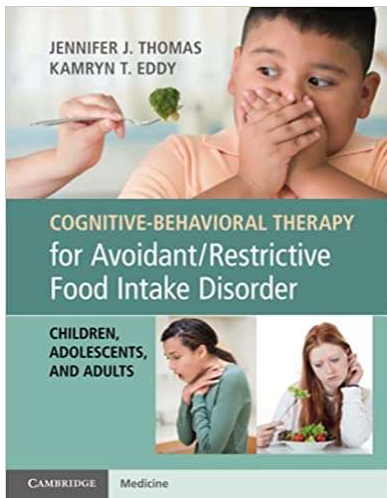
- Ages 10 years and up

Emerging evidence for treatment

- Feasible, acceptable
 - Average of 20-24 sessions (depending on degree of underweight)
 - High treatment satisfaction
 - All 17 youth who completed treatment were rated by clinician as much or very much improved (Thomas et al., 2020, *International Journal of Eating Disorders*)

33

CBT-AR



- › Outpatient Approach:
 - › Individual
 - › Family-supported
- › Stages (20-30 sessions):
 - › 1. Psychoeducation and early change
 - › 2. Treatment planning
 - › 3. Focus on maintaining mechanisms
 - › 4. Relapse Prevention
- › This might not be a good fit if there are other concerns, like active suicidality, substance use, dependence on tube feeding

34

Accompanying Workbook - Handouts



What is ARFID?
Avoidant / Restrictive Food Intake Disorder

ARFID is different from other eating disorders, like anorexia nervosa, because people with ARFID do not worry much about how they look, or how much they weigh. Instead, people with ARFID might have one, two, or all three of these important concerns:

1. Some people with ARFID find that novel foods have strange or intense tastes, textures, or smells, and they feel safer eating foods that they know well.
2. Others have had scary experiences with food, like throwing up, choking, or allergic reaction, so they may avoid the foods that made them sick, or stop eating altogether.
3. Still others don't feel hungry very often, think eating is a chore, or get full very quickly.

Thomas, J.J. and Eddy, K.T. (2019). *Cognitive-Behavioral Therapy for Avoidant/Restrictive Food Intake Disorder: Children, Adolescents, & Adults*. Cambridge: Cambridge University Press.

35

Family-Based Treatment for ARFID (FBT-AR)

- > Similar to FBT for anorexia nervosa and bulimia nervosa
 - > Tools for caregivers to support their child's recovery and to make decisions about eating
 - > Goal: increase variety in food consumption (and weight, if relevant)

Fitzpatrick et al., 2018

36

- › Emerging evidence for feasibility & acceptability of FBT-ARFID (Lock et al., 2020)
- › Increases in parent self-efficacy for FBT-ARFID



37


Options for Treatment/Support

- › First book aimed at adults with ARFID



38


Handout for families





Supporting children and youth with restrictive eating: Information for parents

Parents/caregivers have expertise about their child and are key active partners in supporting their child to their full potential. There is no evidence that parents cause eating problems. Instead, family life may change when there is a child with restricted eating (e.g., trying to accommodate a child's preferences or routines).

- Many types of restrictive eating develop from a combination of a biological predisposition (e.g., sensory sensitivities, increased awareness of physical sensations, lack of hunger cues or interest in eating) interacting with psychosocial factors (e.g., negative experiences related to food, food beliefs).
- **Take the pressure of at mealtimes and meet your child where they are at.** Your responsibility as the parent is to provide the food, your child's responsibility is to decide what and how much of it they want to eat, and to be polite about non-preferred foods.
 - Note: This may look different if your child is underweight/nutritionally compromised – ask your clinician for more information.
- **Prioritize positive family mealtimes:** Family meals that are a positive time to connect can be helpful in many ways! Research shows that family meals (even just 3 or more times a week) are an opportunity for connection that lead to better physical and mental health. Coasting, threatening, or focusing on what your child is or is not eating is unlikely to increase their variety/volume, in fact, it may increase the negative association your child has with food. Attend to the positives in their behaviour and keep conversation on neutral or positive topics.
- Give **opportunities for exposure** to new foods, and make sure that snacking/grazing between meals does not interfere with feeling hungry at mealtime.
- Use **nonjudgmental words** to describe foods, especially foods that are new or not preferred. Resist the urge to describe foods as "good", "bad", "healthy", "unhealthy" etc. Instead, focus on neutral qualities to describe the food: is it crunchy or smooth? What colour is it? What texture is it?
- Even if the reason behind the restrictive eating is not related to weight or shape, we can still be mindful about how we talk about these factors:
 - Some youth who lose weight because of restrictive eating find they get praised for their slim appearance, which then reinforces the belief that body size is important.
 - Pressure and judgmental language around food and eating can make it harder for a young person to approach a new food or may bias their experience of the food.



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Questions?

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Thank you for joining.

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