SPACE TO BREATHE THERAPY

# A Parent's Guide to Supporting a Child with ARFID

Understanding your child, protecting nourishment and building safety around food

A compassionate guide for parents and carers

CHAPTER 01

# How to use this guide

This guide is for parents, carers and other adults supporting a child or young person whose eating is restricted or feels frightening, exhausting or unpredictable. It is written to help you understand what may be happening, protect nourishment and connection, and prepare for conversations with professionals. It does not replace an individual assessment, nutrition plan or medical advice. Children differ, and the same child's needs can change with health, stress, development and setting.

You can read from the beginning or turn to the page closest to today's difficulty. The practical prompts are not tests and do not have to be completed. Choose ideas that fit your child and family; leave anything that increases pressure or conflicts with the child's care plan. Some pages discuss illness, choking fears, vomiting and urgent health concerns. Pause, skip or read with another adult if that feels steadier.

The guide separates general information from Maggie's personal experience in a section called "From My Side of the Table'. Her story is one person's account, not a template for every child. A child does not need to have the same sensory profile, safe foods or feelings to have real support needs. Where possible, let the child use their own words, communication system, gestures, drawings or choices to explain what eating is like.

The resources and service information are UK-focused. NHS pathways differ across England, Scotland, Wales and Northern

Ireland, and local services vary. If your child is medically unwell or cannot keep fluids down, seek prompt clinical advice rather than relying on this guide. If there is an immediate emergency, call 999. You do not have to wait for a diagnosis to ask a GP, health visitor, school nurse or paediatric team for help.

You may find it useful to keep a running list of questions rather than trying to remember everything during an appointment. Write down the answer you receive and who gave it, especially if different services are involved. If advice is unclear, ask the professional to explain it in another way or put it in writing. The guide is not asking you to become your child's clinician or dietitian. Your role is to share what you notice, support your child's communication and seek appropriate care. You are allowed to need help understanding a plan too.

### IN PRACTICE

Pick one page that matches the concern you have today. Write down one question you want to ask and one person you could ask. Keep the guide nearby, but let your child's clinician advise on medical and nutrition decisions.

### PAUSE & REFLECT

What would help our family most right now: understanding, a plan, support for me, or a safer conversation with my child?

CHAPTER 02

# Understanding ARFID

ARFID means Avoidant/Restrictive Food Intake Disorder. It involves avoiding particular foods, restricting the amount eaten, or both, in a way that has a significant effect on nutrition, growth, health or everyday life. Unlike eating disorders primarily driven by weight or shape concerns, ARFID restriction is not undertaken to change body size. Sensory experiences, fear of an unpleasant consequence, low interest in food, or a combination can be involved. [1,2]

A child may eat too little, have a very narrow range, depend on supplements or need support to manage meals outside home. Another child may eat a range that looks reasonable but not enough volume or variety to meet their needs. Some children manage familiar routines yet struggle at school, on trips or when a product changes. The label describes a pattern that needs understanding; it does not explain every reason a particular meal is hard.

ARFID is not a parenting failure, a deliberate attempt to upset adults, or simply stubbornness. A child may want to eat and still experience a genuine barrier: a smell that overwhelms, a swallowing fear, nausea, weak hunger cues or a body sensation they cannot easily describe. The visible response may be refusal, gagging, freezing, leaving the table, asking for a familiar brand, or becoming distressed before the food is served.

The diagnosis is made by a qualified professional after considering the child’s history, health, eating pattern and impact. A parent can notice concerns and seek help without deciding the diagnosis in

advance. Avoid using a checklist to label a child. Instead, bring concrete observations: what foods are manageable, what happens around eating, how long it has been happening, what has changed and how it affects the child's body and participation.

The word "disorder' can sound as though something is wrong with a child as a person. It refers to a pattern of eating that can create important health or daily-life effects and deserves care. It does not tell you what caused the difficulty, how severe it is today, or what treatment will suit. A professional may consider how long the pattern has been present and whether the child can meet nutritional needs, maintain health and participate in ordinary activities. Keep the focus on the child's needs rather than on proving whether the label fits.

### IN PRACTICE

Write a brief "what we notice' note: the main concern, when it began, current reliable foods and drinks, recent changes, and what daily activities are affected. Keep it descriptive rather than calling the child fussy or difficult.

### PAUSE & REFLECT

What might my child's behaviour be communicating about the experience of eating?

CHAPTER 03

# ARFID and ordinary food neophobia are not the same thing

Many children go through periods of caution with unfamiliar foods. They may prefer familiar meals, need repeated low-pressure exposure or reject something one day and accept it another. ARFID is different when restriction has a more serious impact on nutrition, growth, health, dependence on supplements or daily functioning. A child's distress and impairment matter; the number of foods alone does not settle the question.

There is no simple home test that separates ordinary developmental caution from ARFID. Consider the pattern over time: Is the range narrowing? Is the child missing school meals, parties or trips? Are family routines organised around avoiding distress? Is eating accompanied by panic, pain, gagging or strong sensory discomfort? Is the amount eaten sufficient for the child's needs? These observations help a clinician decide what assessment is appropriate.

Comparison can mislead. One child's accepted list may be short but cover enough needs for them; another child may have a longer list yet avoid whole food groups or eat too little. Children also differ in age, health, body size, growth pattern, activity, allergies, disability and cultural food practices. A sibling's eating is not a useful benchmark for deciding whether this child deserves help.

Parents are sometimes told to wait until a child is hungry enough or to stop offering familiar foods. That advice may not fit ARFID and can increase distress or reduce intake. If you are concerned, seek individual guidance instead of escalating pressure at home. You can tell a professional, “I know children can be cautious with new foods, but this pattern is affecting our child in these specific ways.’

A parent may hear “all children are fussy’ or “they will grow out of it’. Such comments can make it harder to ask for support, especially when the child is still growing or appears outwardly well. You can explain the specific impact without arguing over labels: the child is not eating at school, the food range is shrinking, distress is rising, or social activities are being avoided. A clinician can assess the pattern. Early questions are reasonable; you do not need to wait until family life has become a crisis.

### IN PRACTICE

Make two columns: “what is hard’ and “what it is affecting’. Include health, energy, school, social life and family stress. This can help a GP understand why you are seeking advice.

### PAUSE & REFLECT

What am I comparing my child with, and what information about my own child matters more?

CHAPTER 04

# The sensory pathway

For some children, sensory features are a major barrier. Smell, flavour, colour, appearance, texture, temperature, sound, mixed foods, foods touching, packaging, brand or preparation can change whether a food feels possible. A slight change that an adult barely notices can make a familiar item seem unfamiliar. A child may gag, feel sick, freeze, retch or feel unable to swallow; those responses are not necessarily chosen or under simple control.

Sensory preferences are individual. One child may prefer crisp, dry foods; another may manage smooth foods but not pieces; another may avoid strong smells or food that changes temperature. Do not infer a pattern from one meal. Notice what is consistent and ask the child to show or choose between descriptions if they do not have words. “Too wet’, “too strong’, “the bits feel wrong’ or a gesture toward the mouth can all be useful information.

The environment matters as well as the food. Cooking smells, buzzing lights, noise, people chewing, crowded rooms, a hot kitchen, bright plates or rushed transitions can make eating harder. A child may cope with the same food in one place and struggle in another. Observing the whole context prevents every difficulty being treated as proof that the child dislikes the food itself.

Accommodations can make eating more accessible: predictable brands, separated foods, a familiar plate, reduced cooking smells, quieter seating, a realistic meal length, or an accepted option alongside other food. These supports do not automatically prevent

progress. If food exploration is part of care, a clinician can help decide what to keep stable and which small sensory step may be appropriate.

Sensory reactions are not a preference that an adult can correct by insisting. A child may experience a food as intensely sour, slimy, gritty, fibrous, mixed or unpredictable; a smell may fill the whole room for them. Avoid asking them to prove a sensation by eating the food. Instead, ask what they notice and whether they can point to a sensory description. If they cannot explain, you can still adjust the environment and record what you observed for a professional discussion.

### IN PRACTICE

For several meals, note food properties and surroundings: brand, temperature, texture, smell, presentation, noise, time pressure and who was present. Look for patterns without asking the child to perform a tasting task.

### PAUSE & REFLECT

Which sensory details does my child notice that I may not experience in the same way?

CHAPTER 05

# Fear-based ARFID and frightening food experiences

Some children avoid eating because they fear choking, vomiting, pain, an allergic reaction or another frightening outcome. The fear may follow a distressing event, or it may grow gradually as the child notices a body sensation and becomes afraid it will happen again. Avoidance can feel protective. Reassurance may help briefly, but may not remove the body's alarm response or restore confidence on its own.

A child may eat only foods they believe are easy to chew or swallow, ask for repeated checks, avoid eating when alone, or become distressed when a meal is mentioned. They may scan for danger, take tiny bites, chew for a long time, spit food out, or avoid a setting where a previous episode happened. Do not assume the child is exaggerating because the feared event seems unlikely to you.

First consider health and safety. New swallowing difficulty, pain, repeated vomiting, suspected allergy or other physical symptoms need assessment by an appropriate clinician. A parent should not decide that symptoms are "only anxiety' or try to test a serious reaction at home. Once medical issues have been considered, a qualified professional can help distinguish fears and plan support at a pace that respects the child's needs.

Some evidence-informed treatments use gradual, collaborative practice with feared situations or foods. The steps, pace and safeguards should be individualised. Surprise exposure, forcing a

bite, hiding an ingredient or withholding accepted food can damage trust and may intensify fear. A child should know what is happening and have a way to communicate distress. Ordinary meals can remain focused on nourishment rather than becoming an unplanned therapy session.

A child may know that avoiding the food reduces fear in the short term, while still feeling frustrated about what they cannot do. Telling them that the fear is silly or that nothing bad can happen may leave them feeling alone. Acknowledge the fear without confirming an unverified danger: “I can see you are worried. We will check what your body needs and ask the right person.’ If an event such as choking or vomiting has occurred, describe it accurately to the clinician rather than trying to make the child revisit it repeatedly at home.

### IN PRACTICE

Record the child’s own words about the feared outcome, what they avoid and what feels safer. Share this with the GP or specialist team; do not create a home exposure plan from this page alone.

### PAUSE & REFLECT

What would help my child feel believed while we find out whether medical assessment or specialist support is needed?

CHAPTER 06

# Low interest, small appetite and interoception

Some children do not often feel hungry, become full quickly, forget to eat while focused on another activity, or experience eating as effortful. Hunger may not arrive as a clear signal. A child might instead become irritable, tired, headachy, shaky or nauseated, or only realise they need food after their energy has dropped. These experiences can be hard for a child to connect with eating, especially if they have differences in interoception—the awareness of internal body signals.

Adults may interpret low interest as not caring, but a child can be undernourished or distressed without asking for food. Waiting until hunger is obvious may not work for every child. Predictable eating opportunities, visual routines, reminders or a supportive adult presence may help some families, but the right schedule and nutrition plan should be discussed with a clinician or dietitian who understands the child's health and development.

A routine should be workable, not punitive. It can reduce the number of decisions a child has to make and help parents remember what has been agreed. Avoid repeatedly asking "Are you hungry?' if the child cannot read that signal. Try a neutral choice about timing, location or which familiar option is available, while following any individual care plan. A child may also need time away from a highly absorbing activity before eating is possible.

Low appetite has many possible contributors, including illness, medication effects, pain, constipation, sleep, anxiety, sensory demands and other health issues. It deserves curiosity rather than blame. Share changes in appetite, energy, fullness and eating pace with a health professional. If the child is losing foods, struggling to drink, or showing worsening physical symptoms, seek advice promptly.

A child may not notice hunger until a routine is interrupted or the body is already depleted. They may also feel full quickly or find chewing and swallowing tiring. These observations can be useful to a paediatric or dietetic team, but they do not show by themselves whether the cause is interoception, medication, a physical condition or something else. Keep the approach predictable and calm, and ask the team to help decide how timing, portion size and fluids should be managed for this child.

### IN PRACTICE

For one week, note meal opportunities, what was manageable, energy and any body signals the child mentions. Avoid recording bites as a score. Ask the professional team whether a predictable routine or a different assessment would help.

### PAUSE & REFLECT

What signs might tell us that my child needs food or a break before they can name hunger?

CHAPTER 07

# Mixed presentations and changing needs

The sensory, fear-based and low-interest patterns are helpful ways to think, not boxes a child must fit into. Many children experience more than one pathway. A child may have strong texture sensitivities, fear vomiting after a painful episode and rarely notice hunger. Each pathway can affect the others: fear may reduce intake, an empty stomach may increase nausea, and sensory overload may make it harder to eat enough.

The pattern can change over time. Illness, stress, puberty, school transitions, fatigue, medication changes, constipation, a choking episode, a change in safe food or sensory overload can alter what is manageable. A child may cope well at home but not at school, or manage breakfast but not dinner after a demanding day. A change is information to investigate, not evidence that the child is manipulating adults.

Try to avoid turning one explanation into the whole story. If a child is autistic, not every food difficulty is automatically sensory. If anxiety is present, physical symptoms still deserve attention. If a child has a safe food, that does not mean all of the problem is preference. Considering more than one contributor helps the family and clinical team avoid both dismissing a real barrier and making unsupported assumptions.

A useful care plan can name what is known, what remains uncertain and what would prompt review. For example, it may note that

school noise is a clear barrier while the reason for nausea is still being assessed. You can ask professionals how the plan will be updated when the child's health, developmental stage or circumstances change.

Instead of asking the child to choose one reason, ask what was different in this specific moment. The answer may be "I felt sick', "it smells wrong', "I was tired', or "I don't know'. Not knowing is an acceptable answer. Adults can use observations to identify patterns while remaining open to more than one explanation. If a new symptom appears, especially pain, vomiting or swallowing difficulty, arrange medical assessment even if the child has an established ARFID diagnosis.

### IN PRACTICE

Draw three overlapping circles labelled sensory, fear and appetite/body signals. Add examples from your child's experience, and leave space for "not sure yet'. Use it to guide questions, not to diagnose.

### PAUSE & REFLECT

What has changed recently, and which parts of the pattern are still uncertain?

CHAPTER 08

# Autism, ADHD and other neurodivergent needs

ARFID and neurodivergence can occur together, but neither automatically causes the other. An autistic child may have sensory differences, a strong need for predictability, difficulty with change or communication needs that affect eating. ADHD may make it hard to notice time, shift away from an absorbing activity, organise a meal or remain with a task. These are possible interactions, not a description of every autistic or ADHD child.

Support should make eating more accessible rather than requiring a child to hide their needs. A visual sequence, consistent presentation, low-demand language, familiar cutlery, clear transition warnings or a quieter place may help. The child's communication style matters: some can explain a sensation, others may point, use symbols, sign, write, or only communicate once they are calmer. Adults can offer concrete choices without demanding a long explanation.

If a child has sensory needs around food, consider the whole experience: lighting, noise, smells, touch, seating, temperature and social expectations. If executive-function demands are high, simplify steps and reduce waiting. If a child is distressed by uncertainty, tell them what will be served and what can change. Changes should be explained honestly; do not secretly swap ingredients or products.

The best adaptations are individual. Ask the child what helps and review whether the support improves access, safety or

participation. A professional familiar with both eating disorders and neurodivergence can help distinguish accommodation from treatment goals. Parents should not be expected to remove every difference from the child; support can preserve dignity while addressing medical and nutritional needs.

Sensory accommodation is not “giving in’ when it makes access possible. A quiet seat, known brand, separate foods or a visual routine can reduce a barrier enough for a child to take part. The support can be reviewed with the team if it no longer meets health needs or if the child wants to work toward a change. Review means asking what the child experiences, not removing an accommodation to see what happens. Avoid assuming that every autistic child needs the same plate, routine or social setting.

### IN PRACTICE

Ask the child to choose from ways of communicating: speaking, pointing, drawing, typing or answering one question at a time. Note which adjustments help them eat or stay present.

### PAUSE & REFLECT

How can we adapt the task or environment instead of asking my child to mask a need?

CHAPTER 09

# Before we add variety: nourishment and health

A child needs enough nourishment and fluids to support health, growth, learning and daily activity. Parents may be understandably worried when the diet is narrow, but an online nutrition chart cannot tell you whether an individual child is meeting their needs. A paediatrician or dietitian can review growth over time, intake, supplements, hydration, gastrointestinal symptoms, medication and other health factors.

A child can have a significant nutrition concern at different body sizes. Appearance is not a reliable assessment of intake, growth pattern, nutrient status or physical stability. If you notice a change in growth, weight, energy, concentration, dizziness, bowel habits or ability to take fluids, share it with a clinician. Avoid using a child's body size as reassurance that there is no problem or as a reason to delay assessment.

Protect foods and drinks the child currently manages while the team assesses adequacy. A clinician may recommend supplements, blood tests, a dietetic review or other medical checks depending on the child. Do not start or stop supplements, exclude whole food groups, or use online calorie targets without individualized advice. Some children have allergies, intolerances or medical conditions that also need assessment; ARFID does not rule those out.

Parents can help by bringing a current list of reliable foods and drinks, product details where relevant, typical meal patterns,

supplements, symptoms and recent changes. This information supports care; it should not become surveillance or a way to pressure the child. Ask which physical signs require a routine appointment, prompt review or urgent help, and write that plan down.

Nutritional assessment is more than looking at one meal or one measurement. Growth and health are considered over time alongside the child's intake, symptoms and circumstances. A parent can ask what is being monitored, how often it will be reviewed and what would prompt a change in the plan. If a child takes a supplement or prescribed nutrition product, ask the clinical team how to use it and what to do if it is refused. Do not change the amount or type without advice.

### IN PRACTICE

Prepare a health summary for the clinician: current foods and drinks, supplements, symptoms, recent changes, medication and concerns about energy or growth. Do not estimate nutrition if that would add pressure; ask the dietitian what information is useful.

### PAUSE & REFLECT

What health question needs a qualified professional's answer rather than guesswork at home?

CHAPTER 10

# Safe foods are a bridge to nourishment

A safe food is an item a child can currently manage with more predictability than other foods. It may be familiar in taste, texture, temperature, brand, smell, appearance or preparation. Safe foods can carry real nutritional and emotional importance. When eating is difficult, a reliable food may be what allows a child to eat something, join a meal or get through a school day.

Parents can feel both relief and fear when the accepted list is small. You may worry about variety, nutrients, the product being discontinued or another adult judging what you serve. Those worries deserve support, but removing reliable food to force variety can reduce intake and damage trust. Protect nourishment while you seek professional advice about nutritional adequacy and longer-term goals.

Keep track of details that make a food dependable: exact brand, packet, preparation, temperature, shape, portion, plate or container. A replacement that looks similar to an adult may taste or feel very different to the child. When stock changes, tell the child honestly and involve them in finding an alternative if possible. Do not make a hidden ingredient change as a test.

A safe food is not a promise that the child will eat it every time. Appetite, illness, sensory load, tiredness and changing tolerance can affect what is possible. If a food stops working, stay curious and consider whether anything changed in the product, the child’s body

or the setting. The aim is not to keep the child dependent on a tiny range; it is to build a secure base from which support can grow.

Parents sometimes feel embarrassed about packing the same food again or bringing a familiar option to a family event. A child should not have to earn access to a reliable food by tasting something unfamiliar. When adults make safe food conditional, the child may learn that nourishment is uncertain. You can keep one familiar option available while professionals help assess whether the overall diet meets the child's needs. The child's range can be supported over time without turning each meal into a contest.

### IN PRACTICE

Start a Safe Food Passport: product and brand; preparation; temperature; texture and smell; presentation; accepted container; known alternatives; and any physical reactions to discuss with a clinician. Keep it practical and update when something changes.

### PAUSE & REFLECT

How can I protect what currently helps my child eat while we learn what additional support is needed?

CHAPTER 11

# When a safe food changes or disappears

A familiar food can suddenly become difficult for reasons that are subtle to adults: a new recipe, different batch, packaging, shape, temperature, storage, preparation, smell or texture. Sometimes the child's body or sensory tolerance has changed; sometimes stress, illness, nausea or an upsetting experience has altered the association. A child may not know why the food feels different and may only be able to say "wrong', "not that one' or "I can't'.

Try not to respond with "But you ate it yesterday' as if yesterday's experience settles today's. Acknowledge the change and check what the child notices. Compare the packet and preparation, ask where the difference feels strongest, and consider physical symptoms. Avoid repeatedly presenting the food to prove whether it is safe; the child can experience that as pressure and the family may learn little from it.

If the food is an important source of nourishment, contact the dietitian or medical team for help planning alternatives. Keep other reliable foods available while you investigate. If the child reports a possible allergic reaction, swallowing difficulty, pain or repeated vomiting, seek medical advice rather than assuming this is sensory avoidance. Equally, avoid removing many foods at once without professional guidance; unnecessary exclusions can make a narrow diet harder to manage.

If the exact product is unavailable, let the child know what you have found and offer meaningful choices. A photo, package, label or ingredient list may help them compare options. Do not disguise one product as another. Trust is part of safety, and a child needs accurate information to decide what feels manageable.

If a familiar food is being lost, check practical details before proposing a replacement: same brand, batch, storage, temperature, preparation and container. Ask the child whether the package looks or feels different. If the food is no longer manageable, acknowledge the disappointment and move to the agreed backup plan. Parents should not insist the child eat it because money has been spent or it was previously accepted. Keep the packaging if a clinician or manufacturer needs details about a change.

### IN PRACTICE

Use a Food Change Record: what changed; what the child noticed; body symptoms; whether the food was eaten in another setting; safe alternatives; and who you will contact if intake is affected.

### PAUSE & REFLECT

What might I investigate before I conclude that my child is refusing for no reason?

CHAPTER 12

# The mealtime environment

The meal begins before the plate arrives. Cooking smells, noise, bright light, a busy kitchen, fatigue after school, time pressure, unexpected visitors or a rushed transition can affect whether eating feels possible. Adults may enter the room worried about intake, while a child anticipates prompts or disappointment. The emotional atmosphere can add demands to a task that is already hard.

Look for simple changes that reduce unnecessary load: give a short warning before the meal, tell the child what will be served, keep familiar tableware available, reduce cooking smells if possible, offer a quieter seat, and avoid making the meal longer than the child can manage. Some children prefer eating with others; some eat more comfortably in a quieter setting. Ask the child rather than applying one family rule to everyone.

Reducing pressure does not mean ignoring nutrition. It means following the agreed plan without adding bargaining, threats, public bite-counting or repeated commentary. If a clinician has set a specific eating schedule or support routine, follow that plan and ask the team about any part that is difficult. Parents should not have to improvise a nutritional strategy during every stressful meal.

A family meal can be flexible. People may eat different foods, sit together for part of the meal, or join conversation while the child eats a reliable option. Connection and food variety do not have to be measured at the same time. Over time, a calmer predictable setting may make it easier to notice which food or sensory steps are

genuinely difficult.

A predictable table does not require a silent, rigid or perfectly arranged meal. It means the child has enough information and fewer avoidable surprises. Some families may find a shared meal helpful; others may need a temporary adjustment so the child can eat safely. Consider whether food discussion can happen outside the meal and whether other adults can stop watching the plate. The child can still be included in family conversation even when their food or eating time differs.

### IN PRACTICE

Make a Calmer Table Plan with the child: where they sit; which safe food is available; difficult sounds or smells; a pause signal; a realistic time; and what adults will do if eating is hard.

### PAUSE & REFLECT

Which part of the environment could we change without making the child responsible for calming everyone else?

CHAPTER 13

# Language that protects trust

The child can hear the meaning behind a comment even when adults intend to encourage. “Just one bite’, “you ate that last week’, “look how well your sister eats’ or “you will get dessert when you finish’ can turn eating into a performance. Comments about waste, body size, nutrition or being difficult may add shame. Parents do not have to speak perfectly; they can notice the effect and repair when a conversation has become pressured.

Try neutral observations and open questions. “I can see this feels hard’; “Would you like the familiar plate?’; “Is the smell, texture or something else bothering you?’; “You can show me instead of explaining’; “I’ll follow the plan we agreed.’ Offer no more choices than the child can process. A question is not neutral if the only acceptable answer is the one an adult wants.

Respectful language does not mean every request can be granted or that health needs disappear. Parents can hold a clear boundary around safety while avoiding blame: “We need to follow the plan for your medicine; would you like water or your usual drink?’ If there is a medical concern, explain what adults are doing and why in language suited to the child’s age and communication needs.

If you have commented, bargained or become frustrated, repair simply: “I was worried and I put pressure on you. I’m sorry. You are not in trouble. Let’s talk with the team about what would help.’ A repair does not erase the moment, but it shows the child that their experience matters and that adults can take responsibility too.

Praise can also create pressure when it is focused only on bites, amount or trying a new food. A child may then feel that an adult's approval depends on eating. You can notice effort without rating the meal: "You told me the smell was hard'; "You asked for the plate you needed'; or "We followed the plan together.' If a clinician has set a measurable health target, discuss how adults can support it without making the child feel publicly evaluated.

### IN PRACTICE

Choose three phrases your family can use when eating is difficult and agree on two phrases you will try to stop using. Put the helpful phrases somewhere caregivers can see them.

### PAUSE & REFLECT

What does my child need to hear from me when they are already struggling?

CHAPTER 14

# Food exploration without turning every meal into therapy

A child may learn about an unfamiliar food through looking, tolerating it nearby, noticing its smell, touching it, moving it with a utensil or choosing to taste. These are possible steps, not a mandatory ladder that every child must climb. Some children do not want to engage with a food yet; others enjoy cooking or serving food but do not want to eat what they make. Participation should not be presented as a hidden route to a bite.

If exploration is appropriate, plan it separately from ordinary nourishment and agree what will happen beforehand. A short, predictable activity with a clear end can feel different from an unexpected challenge at dinner. Keep a reliable food available. The child should know that touching or tasting is optional unless their clinician has set a specific, agreed treatment task. Celebrate communication and choice, not just eating.

Do not hide food in a familiar dish or use surprise ingredients to get a child to eat more. If the child discovers the change, trust in the familiar food may be lost. Tell them what is in the food and how it was prepared. A child should be able to decline a learning food without losing access to nourishment or affection.

Parents can observe curiosity without assigning progress points. A child may ask a question, tolerate the smell, help choose a product or communicate a boundary. These moments can inform care, but they do not prove recovery or guarantee that a food will be

accepted next time. If exploration reliably causes panic, gagging or a drop in intake, stop and ask a qualified professional to review the plan.

Playful exploration can be useful for some children, but it is not automatically suitable. A child might enjoy arranging, smelling or learning about food and still not be ready to taste it. Keep the activity genuinely optional and separate from rewards, threats or the promise of a favourite food. If a child shows escalating distress, stop and ask the professional team whether the activity should be changed. The adult's goal should be understanding and safe support, not persuading the child to reach a predetermined step.

### IN PRACTICE

If exploration is part of the child's plan, agree the food, setting, time limit, choice of activity, safe food and stop signal together with the clinical team. Record what the child said helped.

### PAUSE & REFLECT

How can we make curiosity possible without making the child feel tricked or tested?

CHAPTER 15

# Food chaining and graded support

Food chaining is sometimes used to describe exploring foods that share familiar qualities with an accepted food, such as texture, shape, brand, temperature or flavour. It is not a recipe for moving every child through a fixed sequence. A clinician or dietitian who understands ARFID can help decide whether it is suitable, which similarity matters to the child, and how any nutritional goals fit the plan.

A small step may involve noticing a different packet, comparing two shapes, serving a familiar food in a new place or simply having a learning item on a separate plate. For another child, even these changes are too large at the moment. The appropriate step is one the child and clinician agree is safe and manageable□not the smallest change an adult can imagine.

Do not disguise changes, remove the familiar version, insist on a bite or make the child hungry before an exposure. Those strategies can turn a learning task into a threat and may reduce intake. If a child is highly distressed, stop the practice and follow the care plan. Ordinary meals should continue to offer nourishment rather than becoming a repeated experiment.

Progress can be non-linear. A food may be tolerated one day and difficult the next; a child may expand in one context but not another. Review what helped, what felt too much and whether the step still makes sense. A clinician can adjust the pace and check

whether medical symptoms, anxiety, sensory barriers or another factor need attention.

A plan can also include how adults will know a step is too much. Signs may include panic, gagging, shutting down, fleeing, escalating distress or reduced intake afterward. Agree a stop signal and a recovery plan with the clinician and child. If practice increases distress or affects reliable eating, report this rather than pushing through. A useful approach is one the child can understand and the team can review. No child needs to demonstrate bravery for a parent to take a concern seriously.

### IN PRACTICE

Use a three-part record only for clinician-agreed practice: planned step; child’s experience and stop signal; what the team should review. Do not use the record to score compliance.

### PAUSE & REFLECT

What would make this step collaborative, predictable and safe for my child?

CHAPTER 16

# Working with school and childcare

School may create barriers that are not visible at home: noise, smells, crowded lunch halls, short eating times, food policies, unfamiliar staff or worry about peer comments. A child may manage a familiar meal at home and eat very little at school. Ask what happens before, during and after lunch rather than assuming the packed food is refused for the same reason every day.

Arrange a conversation with the school's appropriate lead, such as the SENCO, school nurse or pastoral staff, depending on local arrangements. Explain that ARFID can affect eating and participation; share only information needed to support the child. Ask how staff will provide agreed foods, a quieter space, extra time, predictable routines, safe storage or help if food is lost. Ensure staff do not use public praise, punishment or "one more bite' pressure unless a qualified care plan specifies an approach.

A written plan can name the child's safe foods, sensory needs, communication preferences, known medical concerns, what support helps and who to contact if intake is low. Include what staff should not do, such as hiding ingredients or comparing the child with classmates. If the child uses assistive communication or needs extra processing time, describe how adults can check understanding without demanding a verbal explanation.

Review how the plan works. Ask the child what feels helpful or embarrassing and whether they want a trusted adult to accompany

a meeting. If the school says it cannot meet a health need, ask what policy applies and who can discuss adjustments. The exact education and health pathways vary by nation and local authority; seek current local advice if the issue remains unresolved.

The child may worry about stigma or being singled out. Ask them what they want classmates and staff to know and who they trust to help. Staff can often make an accommodation quietly, such as a predictable seat or allowing food from home, without announcing a diagnosis. The school should know which steps are medical requirements and which are preferences to discuss. If the child has a healthcare plan or allergy plan, keep it aligned with the ARFID support plan so staff are not left with conflicting instructions.

### IN PRACTICE

Prepare a one-page school note: reliable lunch options; storage and heating needs; preferred eating place; time needed; sensory triggers; supportive language; signs of distress; and the agreed response if lunch is not managed.

### PAUSE & REFLECT

What does my child experience at school that adults at home may not be able to see?

CHAPTER 17

# Parties, restaurants, holidays and travel

Social events often combine unfamiliar food, smells, noise, waiting and other people's attention. A child may want to join a birthday party but dread the meal. A restaurant can feel difficult because the menu changes, foods touch, portions look unfamiliar or adults expect everyone to eat together. Planning ahead can protect participation without making food the test of whether the child deserves to attend.

Ask the host or venue about ingredients, brands, preparation, seating and whether a safe food can be brought. Keep information simple and discreet; the child can help decide what they are comfortable sharing. At a party, they may eat before arriving, bring a familiar option or join the social part without eating the main meal. Check any health or medication plan with the child's clinician.

Travel can require backup planning: reliable foods in hand luggage or a cooler where permitted, details about storage, a familiar drink, rest breaks, a list of nearby shops and a plan if the usual brand is unavailable. Airline and border rules vary, so verify current requirements. Do not promise a product will be available until you have checked. Explain changes early and offer the child choices where possible.

A flexible plan is not giving up. It can allow the child to stay connected while adults reduce avoidable distress. After an event, avoid asking how many bites they ate as the first question. Ask

whether they felt included, what worked, what was difficult and what they would want to plan differently next time.

Parents may worry that a flexible plan reinforces avoidance. It can help to separate participation from treatment goals. Attending a birthday party with a familiar snack may be a meaningful way to preserve friendship; a clinician-guided food practice can happen at another agreed time. Ask the child which part of an outing matters most and plan around that. Afterward, review the experience without treating the meal as a pass or fail. Their sense of safety and belonging is part of the picture.

### IN PRACTICE

Make an outing plan with three parts: how the child can take part; which familiar food or drink will be available; and what the family will do if the expected food or setting changes.

### PAUSE & REFLECT

How can we make room for belonging without making eating the price of participation?

CHAPTER 18

# Siblings, relatives and other caregivers

Siblings may notice that meals, shopping, travel or family conversation revolve around ARFID. They may feel worried, overlooked, frustrated or confused about why foods and rules differ. Explain that fairness means responding to different needs, not making every plate identical. Give siblings their own time and a safe way to ask questions without comparing what each child eats.

Grandparents, babysitters and relatives may offer advice, praise, pressure or food experiments because they want to help. Tell caregivers what the child reliably eats, which ingredients or reactions need attention, how to respond to distress and who to contact. Make the plan short enough to follow. Agree that nobody will secretly change a food, ask for a bite as proof, comment on the child's body or compare them with others.

Children should not be recruited as food coaches, messengers or monitors. A sibling should not be asked to persuade, reward or watch another child eat. Parents can answer questions in simple, respectful language: "Different bodies and nervous systems find different things difficult. We are getting help and we can all be kind.' Keep private medical details private unless sharing is necessary for care and appropriate.

If a relative dismisses ARFID or continues a behaviour that undermines safety, set a clear boundary and adjust who supports meals. The child's trust and health take priority over an adult's

desire to prove a point. Parents do not need to debate every comment. A short statement “We are following the plan from the team; please don’t change the food’ can be enough.

A sibling can be told that adults are responsible for arranging meals and seeking professional advice. They do not need to persuade their brother or sister, keep secrets about food or carry messages between parents and clinicians. Give siblings a chance to talk about their own experience without making them responsible for fixing the family atmosphere. If they ask why one child has a different meal, explain that different needs can require different support and that everyone deserves respect.

### IN PRACTICE

Write a short caregiver card with three “please do’ actions, three “please avoid’ actions and a contact person. Give it to adults who help with meals, school runs or childcare.

### PAUSE & REFLECT

Who else needs clear information so that my child does not have to defend their needs alone?

CHAPTER 19

# Parent worry, exhaustion and guilt

Supporting ARFID can involve constant planning: checking labels, keeping safe foods in stock, explaining needs to school, managing family reactions and worrying whether the child is getting enough. Parents may feel frightened, guilty or exhausted while still trying to sound calm. Those feelings do not mean you have caused the disorder or that you are failing your child.

Advice to “stay calm’ is difficult to use when there is no clear plan for what to do if intake is low or a food disappears. Ask the clinical team for specific guidance about nutrition, physical symptoms, what belongs at meals, what to do on difficult days and when to seek help. A written plan can reduce the burden of deciding everything in the moment.

Parent support matters in its own right. You may need someone to hear how stressful this is, help you divide practical tasks, or support siblings and other family relationships. Beat offers information and support for people caring for someone with an eating disorder, including ARFID-focused family support for eligible young people; check its current services and criteria. [6,7] Local availability may change.

Try to make space for ordinary family life that is not organised around eating. This may mean a walk, a bedtime story, an activity with a sibling or a conversation about something the child enjoys. It does not require pretending the disorder is unimportant. It reminds

everyone that the child is more than the foods they can or cannot manage.

It is possible to love your child deeply and still feel impatient, resentful or scared. Those feelings do not make you unsafe or uncaring; they are signals that you may need support and a clearer plan. If arguments are becoming frequent, ask for help before the family reaches breaking point. Share tasks with another caregiver where possible, including shopping, school communication and appointment notes. Parent support is not a reward after the child improves; it is part of making care sustainable.

### IN PRACTICE

Write down what you need as a parent: information, practical help, emotional support, time with another child, or rest. Choose one person to ask for one specific thing this week.

### PAUSE & REFLECT

What support would help me keep showing up with care without expecting myself to carry everything alone?

CHAPTER 20

# Assessment: what to bring and what to ask

A first appointment does not require you to know exactly what is wrong. Describe what you have observed and how it affects the child. A clinician may ask about the child's eating history, reliable foods, sensory experiences, appetite, fears, growth, health symptoms, development, school and family routines. The conversation may include the child in a way suited to their age, communication and comfort.

Bring useful records if you have them: a list of accepted foods and drinks, recent changes, supplements, medication, symptoms, school concerns and previous assessments. Keep the information brief and factual. If documenting food increases your child's anxiety, do not turn home into a monitoring project; tell the clinician what you know and ask what further information is necessary.

Ask how the service understands ARFID, what aspects need assessment first, whether a dietitian or paediatric clinician should be involved, and how communication will work between services. Ask what can be done while waiting, who to contact if symptoms worsen and what signs require urgent review. It is reasonable to ask for a summary in writing or to bring another trusted adult if appropriate.

You can say if a recommendation feels unsafe, inaccessible or impossible for your family. Ask what the purpose is, what evidence supports the plan, what alternatives exist and how progress or risk

will be reviewed. The aim is collaborative care that considers physical health, eating-related distress, neurodivergence and the family's circumstances. Services vary across the UK, so the local team can explain its pathway. [3]

If the child is anxious about an appointment, explain the purpose in concrete terms: "We are going to tell the nurse what makes eating hard and ask what can help.' Avoid promising that there will be no examination, blood test or discussion of weight unless the service has confirmed that. Ask the clinic what to expect and whether you can prepare the child in a way that suits their communication. The child should have an opportunity to ask questions and understand why information is being gathered.

### IN PRACTICE

Prepare a page of questions before the appointment. Circle the three most important and leave room to write the answers and the next contact point.

### PAUSE & REFLECT

What do I most need this professional to understand about my child as a person, beyond the food list?

CHAPTER 21

# Building a team around the child

ARFID may involve physical health, nutrition, anxiety, sensory needs, swallowing, development and school participation. Depending on the child, support may involve a GP, paediatrician, specialist eating disorder service, dietitian, psychologist, occupational therapist, speech and language therapist, school staff or another clinician. Not every child needs every professional, and a long list of referrals is not automatically a coordinated plan.

Ask who is coordinating care and who to contact with different questions. The family should not be left to pass messages between services without knowing what information can be shared. Clarify which professional is monitoring growth or medical stability, who advises on nutrition, and who will help with eating-related fear or sensory barriers. If more than one condition is present, ask how the plans fit together.

Parents can advocate without becoming the treatment team. Share observations, ask for explanations, and tell professionals when a plan cannot be followed as written. Be specific: “The school lunch is not happening because the room is too noisy’; “The product changed and this was the only reliable lunch’; “Our child is getting more dizzy.’ That information can help the team revise support.

Keep copies of agreed plans, appointment notes and contact details in one place. If different professionals give conflicting advice, do not choose the most forceful instruction; ask the team to resolve the

difference. The child's safety and nutritional needs should be considered together with trust, communication and family capacity.

A team may include professionals who use different terms or have different priorities. Ask them to state the shared plan in plain language, including what each person is responsible for and when it will be reviewed. If you do not know whom to contact, start with the named coordinator or the child's GP and ask where the question belongs. The family should not be asked to choose between medical safety and emotional safety; clinicians need to consider both and explain how the plan balances them.

### IN PRACTICE

Draw a simple care map: professional or setting, their role, contact method, next action and what needs to be shared. Mark the person coordinating the plan.

### PAUSE & REFLECT

Where are we still being asked to join up information that the professionals need to coordinate?

CHAPTER 22

# Medical symptoms and urgent concerns

ARFID can affect health, but a guide cannot assess a child's medical stability. Contact the child's GP or clinical team promptly if intake is falling, reliable foods are being lost, fluids are difficult, growth changes concern you, the child has persistent pain or vomiting, swallowing becomes difficult, energy drops substantially, or dizziness and weakness are increasing. Explain what has changed and when; do not wait for the child to look unwell or underweight.

Dehydration can become serious. NHS guidance lists signs such as unusual tiredness or drowsiness, dizziness on standing that does not settle, dark urine or less urine than usual, rapid breathing or a fast heart rate; for babies and young children, other signs include fewer wet nappies or few tears. If you are concerned about a child's hydration, seek urgent advice through NHS 111 or the local equivalent. [5]

Call 999 or attend emergency care for an immediate life-threatening problem, such as severe breathing difficulty, collapse, a severe allergic reaction, or a child who is difficult to wake. Follow existing medical advice for allergies, swallowing or other conditions. If you are unsure how urgently to act, call NHS 111 in England or your nation's urgent health service and explain the child's age and symptoms.

Write down the team's individual escalation plan while the child is well. Include whom to call during working hours, out of hours, and

what symptoms mean emergency care. Parents should not have to decide alone whether a worrying physical change is “serious enough’. Seeking advice is appropriate when you are concerned, even if the cause is not yet known.

When you call for advice, useful details include the child’s age, what they can drink, when they last passed urine, symptoms, medication, known health conditions and whether anything has changed quickly. You do not need to have every answer before calling. Follow the professional’s instructions and use emergency services for immediate danger. If a symptom settles, still tell the child’s care team if it is new or has happened repeatedly. This guide cannot tell you whether an individual child is medically stable.

### IN PRACTICE

Fill in the child’s urgent-care contacts and the symptoms the clinical team has asked you to watch. Save the plan somewhere accessible to every caregiver.

### PAUSE & REFLECT

If my child’s health changed tonight, would I know who to call and what information to give them?

CHAPTER 23

# From My Side of the Table: beginning with my experience

I have lived with ARFID since I was nine. I did not begin with a neat explanation of what was happening or a clear way to describe it to other people. Like many children, I could only show what felt possible through the foods I managed, the foods I could not, and the way eating changed across different parts of my life. I am sharing this because parents may find it helpful to hear from an adult who has lived with a very restricted relationship with food.

My experience is not a diagnostic checklist, and it is not everyone's story. ARFID can look different from one person to another. A child may not have the same safe foods I had, may enjoy some foods I did not, or may experience a different mixture of sensory, fear-based or appetite-related barriers. Please do not use my story to decide what your child "should' be feeling. Use it as a reminder to ask them, believe that their experience is real, and stay curious about what you cannot see from the outside.

When a child cannot give a clear explanation, adults can be tempted to decide that the child is choosing not to cooperate. I want parents to leave space for another possibility: the child may not yet have language for a smell, a body sensation, nausea, fear or a sudden change in what feels safe. They may communicate through their actions before they can explain the reason. Listening does not require you to agree with every interpretation; it means treating the communication as worth understanding.

A parent can be frightened about nutrition and still respond with gentleness. If a food is not possible today, the question can be what support the child needs and how to keep nourishment safe while the adults seek advice. I know that not knowing is difficult. But assuming the child is being deliberately difficult can add shame to an experience they may already find frightening.

I share this perspective because adults can miss the effort involved in eating when the child cannot describe it. I am not offering a rule for how parents should behave or claiming that every child feels watched in the same way. Some children want encouragement or company; others need less attention. The child's preference can change from meal to meal. My experience is an invitation to ask rather than assume, and to make room for the possibility that the child is working very hard even when the plate looks untouched.

### IN PRACTICE

If you read this page with your child, ask whether they want to talk, point to a sentence or leave the topic alone. Do not ask them to confirm that Maggie's story is like theirs.

### PAUSE & REFLECT

What does my child communicate about eating that I may need to understand in a different way?

CHAPTER 24

# From My Side of the Table: safe foods and change

There have been periods of my life when the range of foods I could manage was extremely small. At different times, white toast with jam and smooth soups were important because I could manage them. Later, a particular combination of cottage cheese, brown sauce, fried bread and egg yolk became familiar for a while. These examples are specific to me; they are not suggestions for another child's diet or a picture of what ARFID must look like.

Something that works at one point may not keep working forever. In my own life, foods and physical responses have changed. Some foods I once managed later became intolerable, and I have allergies and intolerances alongside ARFID. This is one reason I would not tell a child that they are imagining a physical reaction or assume that every new difficulty is caused by ARFID. Medical questions deserve proper assessment, and unnecessary exclusions also deserve careful professional review.

Safe food can mean predictability, not a favourite or a reward. If a parent removes a reliable food to make a child hungry enough to accept something else, the child may lose the one place they knew they could eat. That does not mean a narrow range should be left without support. It means nourishment and trust need to be protected while clinicians help the family understand nutritional needs and what changes are appropriate.

I would want a parent to ask what makes the food manageable: the exact product, smell, texture, temperature, shape, preparation, or knowledge of what will happen after eating it. The detail may seem small from the adult side of the table and enormous to the person eating. A child may not know how to explain it until an adult shows that the answer will be taken seriously.

My own safe foods were not a plan chosen because they were ideal or convenient. They were foods I could manage at particular times. A parent may look at one food and see nutritional limits; the person eating may see the only reliable route to nourishment today. Both concerns matter, but they need different kinds of help. The child needs protection from pressure, while the adults seek professional support to assess health and widen options where appropriate. My story should not be used to tell a child which foods they ought to tolerate.

FROM MY SIDE OF THE TABLE – LIVED EXPERIENCE

#### IN PRACTICE

Write down what a currently reliable food provides for your child: predictability, energy, a familiar texture, school access, or something else. Ask the clinical team how to protect nutrition and review the diet safely.

#### PAUSE & REFLECT

What might this food be doing for my child besides filling a space on the plate?

CHAPTER 25

# From My Side of the Table: what I want parents to remember

My experience is that what happens around food can affect the experience of trying to eat. When a person already finds eating difficult, being watched, questioned or waited on can make every mouthful feel more significant. Adults may be watching because they are scared and trying to help. From the eating side of the table, the attention can still feel like pressure. I am not saying parents should never notice intake; nutritional concerns need a proper plan. I am asking that the child is not made to feel like a performance is taking place.

There were long periods in my adult life, from around age twenty into my late thirties, when I ate very little. That part of my story reminds me that an eating difficulty can continue beyond childhood and that families may carry worry for a long time. It is not a forecast for your child. A child is not destined to have my path, and a parent’s support can matter without needing to guarantee a simple or linear recovery.

If I could offer one invitation from my own side of the table, it would be to protect trust while seeking help. Tell your child what is in the food. Do not use a safe food as a bargaining chip. Do not promise that a clinician will make them eat everything. Let them know adults are working out what helps their body, and that they can ask questions or say when something feels wrong.

I would also remind parents that they matter. Fear, exhaustion and frustration can be real, especially when every meal feels high-stakes. You deserve support and clear information too. Asking for help does not mean you have failed. It means the family is taking the problem seriously and seeking people who can share the work. My lived perspective sits alongside clinical information; it does not replace the child's own voice or professional care.

I also know that family worry can build over years, and that parents may feel judged by people who see only one meal. You do not have to defend every decision to everyone. It can help to have a short sentence ready: "We are getting advice and following a plan that supports our child's health.' The child should not be asked to carry the family's fear or reassure adults that everything will be okay. Let other adults support you while your child remains a child.

### IN PRACTICE

Choose one trust-building action for the next meal: explain the food honestly, make a safe option available, avoid commentary, or follow the agreed plan. Ask another adult to support you if the worry feels hard to hold.

### PAUSE & REFLECT

What is one thing I want my child to know about my support, even on a difficult day?

CHAPTER 26

# A family observation sheet that does not score food

A short observation record can help a family notice patterns and prepare for appointments. It should not become a daily audit of every bite or a way for the child to prove that they are struggling. If record-keeping raises distress, stop and tell the clinician. Parents can often use brief examples instead of detailed tracking. The purpose is to support understanding, not to place more responsibility on the child.

For a chosen period, note the setting, what was offered, what the child said or showed, and any change in the environment or body. Include sensory details such as smell, texture, temperature, presentation and noise; routine details such as fatigue, time pressure or transition; and symptoms the child reported. Record what helped the child remain present or access a reliable food. Avoid describing the child as naughty, dramatic or manipulative.

Compare easier and harder experiences. Was the same food manageable at home but not in the dining hall? Did the product change? Was the child ill, tired, worried or constipated? Did a familiar adult or a quieter place help? Patterns may suggest questions for assessment, but they do not establish a diagnosis or rule out physical health concerns.

Bring only useful information to the appointment. Ask the clinician how much detail they need and how to share it without making the child feel watched. If the child is old enough, explain why you are

writing things down and what will be shared. Give them a chance to say what they think is missing from the adult account.

A neutral record is most useful when it describes a difference, not a judgement. For example: “Lunch was untouched after a noisy assembly; the child said the room smelled strong; they ate their usual snack in the car.’ This gives a professional something concrete to consider. “Refused again’ does not. You do not need to record every meal indefinitely. Choose a short period or a few examples, then ask whether the notes have helped and whether it is time to stop.

### IN PRACTICE

Use short, neutral observations to prepare a one-page caregiver passport: reliable foods and drinks, preparation and storage, sensory or communication needs, what helps, what to avoid, and who to contact. Keep medical or allergy instructions in the clinician-approved plan. Do not record bite counts unless a clinician asks and explains why.

### PAUSE & REFLECT

How can I gather useful information without making my child feel monitored?

CHAPTER 27

# Plan for a difficult day and a change in food

Difficult days happen for many reasons: illness, fatigue, a stressful school event, sensory overload, pain, constipation, a lost product, travel or a routine change. A plan made in advance can help adults respond consistently rather than negotiating while everyone is distressed. It should be based on advice from the child's care team, especially where nutrition, hydration, allergy, swallowing or medical stability is involved.

A plan can state which reliable options remain available, where they can be found, what to offer if a brand is unavailable, how to make a pause possible and who will contact the clinical team. Decide what adults will say and what they will not do. Avoid threats, punishment, secret substitutions or making the child wait until they are extremely hungry. If the child's intake or fluids are falling, follow the escalation guidance rather than treating it as a behavioural test.

When a product changes, explain what you know. Let the child inspect the packet or choose between realistic alternatives. If possible, keep backup products and note expiry and storage. If a replacement does not work, do not insist that the child prove why. Ask what they noticed and seek help if the loss affects nourishment or daily functioning.

After the day has settled, review the plan with the child and other adults. What made it harder? Was the backup accessible? Did everyone know the response? What needs a clinician's input? A

review should make the next difficult day safer, not assign blame for what happened.

Agree who is responsible for checking stock and replacing a product so the child does not become the household supply manager. Store the backup where caregivers can find it and share instructions with school or relatives. If the child can participate, invite them to help choose the backup without making them responsible for fixing the problem. When an option is unavailable, name the change honestly and follow the plan. Afterward, ask whether the backup worked and update it with the care team if intake was affected.

### IN PRACTICE

Fill in: early sign; reliable foods or drinks; who can help; plan if the food changes; who to call if intake drops; and the signs that need urgent medical advice. Keep it where caregivers can find it.

### PAUSE & REFLECT

If the usual plan stopped working today, what is the next safe action we already agreed?

CHAPTER 28

# Before you leave: one next step is enough

Parents can finish a long guide and still feel unsure. That does not mean the reading has failed. ARFID can involve several pathways at once, and families may be waiting for assessment or trying to coordinate different services. You do not need to solve every aspect of eating before the next meal. Choose one next step that is safe and possible: make an appointment, write down a concern, ask the school one question, protect a reliable food or request support for yourself.

The child deserves to be more than the person everyone worries about at mealtimes. Make room for their interests, humour, friendships, rest and ordinary family connection. This does not minimise health needs. It helps protect the relationship from being reduced to a plate and reminds the child that care is not conditional on eating a certain amount or variety.

If a suggestion in this guide does not fit, you are allowed to set it aside and ask a qualified professional. If a child’s physical condition changes, seek medical advice promptly. If you have been dismissed before, explain the impact clearly and ask what the next assessment step is. Keep asking for help until you reach someone who can consider the child’s physical health, eating experience and support needs together.

From my side of the table, I would want parents to know that a child’s difficulty is real even when it is hard to understand. You can

believe the child, protect trust and seek help at the same time. Progress is not a straight line, and no parent can guarantee how quickly things will change. You can make the next step safer, and you do not have to do it alone.

You can return to this guide when a new situation appears: a school change, a lost food, a holiday or a difficult appointment. You may need different support at different times. Keep the pages that help and share only the information that feels useful. The child's voice, health and dignity belong together. You can be honest about the worry, seek professional support and still make space for warmth, play and ordinary moments that have nothing to do with food.

### IN PRACTICE

Write a note for the week ahead: "One thing I understand better'; "one person I will contact'; "one thing I can pause'; and "one way I will keep connection with my child beyond food.'

### PAUSE & REFLECT

What is the kindest realistic next step for our family this week?

CHAPTER 29

# Sources, terms and support

ARFID is described here in accessible language. It is a recognised eating disorder involving food avoidance, restriction of amount, or both, with clinically significant effects; weight or shape concerns are not the reason for the restriction. Possible drivers include sensory experiences, fear after an aversive event and low interest in food. Every child's presentation and support needs are individual. [1,2]

Selected sources: [1] NHS, Eating disorders overview□ARFID: https://www.nhs.uk/mental-health /feelings-symptoms-behaviours/behaviours/eating-disorders/overview/ [2] Royal College of Psychiatrists, Avoidant/restrictive food intake disorder: https://www.rcpsych.ac.uk/mental-health /mental-illnesses-and-mental-health-problems/avoidant-restrictive-food-intake-disorder-%28arfid %29 [3] NHS England, Eating disorder services for children and young people: https://www.engla nd.nhs.uk/long-read/eating-disorder-services-for-children-and-young-people-national-guidance/

[4] Royal College of Psychiatrists, Medical Emergencies in Eating Disorders (MEED), recognition and management guidance: https://www.rcpsych.ac.uk/improving-care/campaigning-for-better-mental-health-policy/college-reports/2022-college-reports/cr233 [5] NHS, Dehydration: https://www.nhs.uk/conditions/dehydration/ [6] Beat, ARFID information: https://www.beateating disorders.org.uk/get-information-and-support/about-eating-disorders/types/arfid/ [7] Beat, support for families and carers: https://www.beateatingdisorders.org.uk/get-information-and-sup

port/support-someone-else/family-arfid-support/

Terms: “sensory’ describes how a person experiences and responds to sensory information such as smell, sound, texture or temperature. “Interoception’ is awareness of internal body signals, such as hunger, fullness or nausea. “Safe food’ is an informal term for a food a person currently finds more manageable; it does not mean that a clinician has confirmed it is nutritionally complete or medically safe for every person.

This guide is educational and supportive, not an individual diagnosis or treatment plan. It does not replace medical, dietetic, psychological, allergy or emergency advice. Services and eligibility change and differ by UK nation. If you are worried about a child’s hydration or health, contact NHS 111 or your local urgent health service for advice; use 999 for an immediate emergency. Beat provides current information and family support options; check its website for availability and eligibility.

### IN PRACTICE

Save the local urgent-care number and your child’s clinical contact details. Check the service websites for current information before relying on a phone number, referral route or programme.

### PAUSE & REFLECT

What do I want the professionals around my child to understand first?