**Avoidant Restricted Food Intake Disorder (ARFID) CYP Safe Discharge from Dietetic Care - Letter Template from Service to Parent**

*This letter template can be used for those diagnosed with ARFID or for individuals with restrictive and selective eating presentations.*

*To use this letter template, the content below the line should be copied and included after your usual service assessment summary. A typical assessment summary should include the assessment date, details of what the assessment was for, who attended the appointment and who they were seen by. It should also include key assessment information and your rationale for discharge. The text below can then be copied and added. Be sure to check this carefully, make it patient specific and add or amend all relevant information. Then save and close your letter as usual.*

From our assessment, we have identified the following potential risks from [name]’s current nutritional intake:

|  |
| --- |
| Potential short-term risks: [add nutritional/physical] |
| Potential mid- and longer-term risks: [nutritional/physical] |

As [name] will not be receiving follow-on care from our service, and in view of these potential risks, we would advise that ongoing community monitoring is important. This helps to track any changes in [name]’s nutritional or physical health to keep [him/her/them] safe, and to help identify when future access to appropriate services may be required.

We would recommend the following monitoring routine for [name]:

* Check [his/her/their] height in centimetres every 3 months
* Check [his/her/their] weight in kilograms every [week /2 weeks / month]
* Plot [name] height and weight on [his/her/their] growth chart in their Personal Child Health Record Book [or on the growth chart provided]
* [name] should be tracking along the [insert] height centile line\*
* [name] should be tracking along the [insert] weight centile line\*

\* Centile (growth) lines are used to help us monitor changes in weight or height relative to the individual child. Children should increase in height and weight over time to stay on their centile lines and follow their expected growth as they get older.

**Tips and advice for accurate monitoring:**

Monitoring weight and height can sound easier than it is. Our top tips for monitoring an accurate weight include:

* Place the weighing scales on a hard flat floor surface, avoiding carpets
* Scales can vary in accuracy so avoid switching between different scales where possible
* Make sure [name] is stood on the scales completely and isn’t leaning against a wall
* Try to take the weight recording at a similar time of day and in similar clothing. Taking a weight first thing in the morning after visiting the toilet is the most accurate but the most important thing is to find a regular time works well for you and [name]. Therefore, pick a time of time of day, routine, and scales location that best fits for [him/her/them].

Recording an accurate height measure is typically challenging and can often vary. Our top tips for monitoring height include:

* Use a flat wall or door, and one ideally without a skirting board at the bottom
* Position [name]’s heels, bottom and the back of [her/his/their] head also resting against the wall
* Tilt [his/her/their] chin to a 90-degree angle and try to avoid looking up or down
* Position a rigid flat object like a book at the top of the head on the crown (middle). Avoid pushing down too heavily and place it parallel to the floor so that it is not tilting
* Measure where how high the crown of the head is from the floor in centimetres. This will be your childs height. Where possible, take the height reading 3 times and pick the middle height recording

This video from YouTube helpfully demonstrates height and weight monitoring for children at home: [How To Measure Your Child at Home (Age 2 - 18 years)](https://www.youtube.com/watch?v=QxfJ-v2nnY0)

**When to be concerned:**

If [name] is not achieving the above growth and weight targets after [specify according to clinical concern levels] time please make an appointment with [his/her/their] GP to discuss this concern and take your weight/height records with you.

**What if I can’t take my child’s weight?**

If you are struggling to monitor [name]’s weight for any reason, then the circumference of (measurement around) the middle of [his/her/their] upper arm can be used instead. This is known as taking a mid upper-arm circumference reading. To do this:

* Measure the middle distance between the elbow and shoulder
* At the middle point, wrap a soft tape measure around the arm. Ensure it is in contact with the arm without being pulled ‘tight’ and avoid it being so loose that the tape measure is ‘bowed’ with gaps between the skin and the tape. It should be level all the way around the arm.

If using this method, we recommend measuring mid upper arm circumference ever [insert frequency].

This video from YouTube helpfully demonstrates measuring mid upper-arm circumference on a child at home: [Your Tube Study Mid-Upper Arm Circumference Training Video](https://www.youtube.com/watch?v=cGWtRRNveLc).

Hand grip strength can also be used to assess for malnutrition status in when weight monitoring isn’t available. However, this requires a special piece of equipment. If you feel that this may be your only way of monitoring weight, please discuss how this could be supported with [name]’s GP.

**Monitoring Eating**

If [name]’s eating becomes more restrictive you can check if you need to worry using the following self screening tool: <https://kidseatincolor.com/picky-eating-screener>

**When to be concerned:**

If [name]’s nutritional intake significantly deteriorates and their variety or range of foods becomes notably more limited, please return to [his/her/their] GP to discuss re-referral / onward referral.

**Please note** that if [name]’s nutritional intake / number of accepted foods falls significantly then you should still be concerned, even if [his/her/their] weight is stable or increasing. They may be at higher risk for nutritional or physical health deterioration at the following times: puberty, changing school, illness, bereavement or family crisis, or any significant life event.

**Physical Monitoring**

There are several symptoms for you to be aware of and to look out for in [name] that may relate to malnutrition. These include feeling dizzy; experiencing chest pains; noticing few bowel movements or constipation; feeling tired or lethargic; noticing increased skin bruising, sores or delays to healing; experiencing hair loss; feeling unusual muscle aches or pins and needles; or (in girls) noticing that periods have stopped.

In some cases, we would advise that a patient’s GP should monitor a wider set of physical health details. For [name] we feel that this is/is not currently necessary.

[delete section if not applicable]

We therefore recommend the following enhanced frequency of GP monitoring for [name]:

* Sitting and standing blood pressure every [insert]
* Sitting and standing heart rate every [insert]
* Temperature every [insert]
* Biochemistry (bloods) monitoring to include [U’s and E’s, LFT’s, FBC’s] every [insert]
* Biochemistry (bloods) monitoring to assess for baseline deficiency in [iron, folate, ferritin, B12, zinc, vitamin D, calcium, vitamin A, vitamin C] [insert clinical rationale here].

Your GP will need to check these results against the MEED risk assessment framework which can be found here: <https://meed.org.uk/meed-risk-assessment> **and consider appropriate urgent care referrals for any high risk indices.**

**Next steps:**

We recommend that this discharge plan is shared with [[name]’s [GP/any other clinician/school/etc]].

**Self-support:**

[Delete this sentence if the patient has a diagnosis of ARFID] Most of the available public resources list ‘ARFID’ but are useful for those with restrictive eating concerns or ARFID ‘symptoms’.

This patient/carer resource from CNTW has several links and available resources: [Support for Avoidant Restrictive Food Intake Disorder (ARFID) - Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust](https://www.cntw.nhs.uk/resource-library/support-for-avoidant-restrictive-food-intake-disorder-arfid/) with excellent learning and support resources available from [www.bebodypositive.org.uk](http://www.bebodypositive.org.uk) (selective eating and ARFID pages).

The [ARFID Awareness UK website](http://www.arfidawarenessuk.org/) also includes information and resources. The site shop also includes options to purchase cards which help inform schools and restaurants about the disorder.

For carers of children with ARFID, [arfidkids.com](http://www.arfidkids.com/) is a wonderful, comprehensive resource.

Longer webinar videos for parents/carers are available to watch from Aneurin Bevan University Health Board (Wales). LINK?

A range of books is also available including:

* ARFID Avoidant Restrictive Food Intake Disorder: A guide for parents and carers by Rachel Bryant-Waugh
* Helping your child with extreme picky eating by Katja Rowell & Jenny McGlothlin
* Can’t eat, won’t eat by Brenda Legge

 This Instagram account helps to understand support through food chaining: @feedingpickyeaters

The national eating disorders charity [BEAT](http://beateatingdisorders.org.uk/) offers a confidential and inclusive space for anyone who has (or thinks they might have) ARFID. The [Hummingbird Online Support Group](https://www.beateatingdisorders.org.uk/get-information-and-support/get-help-for-myself/i-need-support-now/online-support-groups/arfid-support-group/) currently runs on Sundays 6.45pm-7.45pm. Find out more on the [BEAT website](https://www.beateatingdisorders.org.uk/get-information-and-support/get-help-for-myself/i-need-support-now/online-support-groups/arfid-support-group/) where you can also find [Peer support and online development for carers (POD sessions)](https://www.beateatingdisorders.org.uk/get-information-and-support/support-someone-else/pod-e-learning-platform/) and further information on [Support for Carers](https://www.beateatingdisorders.org.uk/get-information-and-support/support-someone-else/support-for-carers/)

[ARFID Awareness UK](https://www.arfidawarenessuk.org/support-us) also offers [online virtual community support](https://www.arfidawarenessuk.org/support-us) options for individuals or carers.

If you wish to contact a **helpline** you can do so via the BEAT Helpline on: **0808 801 0677** Available Monday-Friday 9am-8pm, and weekends 4-8pm.

**Who to contact if things deteriorate:**

[Insert service specific information here]

[Alternatively, it may be appropriate for you to use the following contact information – delete or re-word as appropriate]

If you become more concerned about your child’s restrictive eating and health, please visit your GP (or health visitor) in the first instance.

If you notice that your child experiences a sudden and rapid restriction of food or fluids that has led to sudden deterioration in their physical health, please seek help quickly. This may include contacting **NHS-111 or emergency care services** **via 999**. Sudden deterioration is often a result of a traumatic event leading to a rapid avoidance of food and/or fluids.

If there is a sudden deterioration in your child’s mental health, or you are concerned about their mental health risks, please contact **your local crisis or emergency care services**. Mental health risks include, but are not exclusive to, suicide and self harm.