Date: 18 May 2026

To:
Sir James Mackey, Chief Executive,
NHS England,
PO Box 16738,
Redditch,
B97 9PT

Subject: Preventable death from malnutrition in children and adults with selective eating – urgent national action required

Dear Sir James Mackey and colleagues,

We write jointly following the recent Prevention of Future Deaths (PFD) report into the death of five-year-old Joshua Allcock, who died from severe dehydration in 2023. The coroner identified undiagnosed avoidant restrictive food intake disorder (ARFID) and missed malnutrition as contributory factors (1).

This is the third PFD report related to malnutrition and ARFID in five years. Seven-year-old Alfie Nicholls died of malnutrition secondary to undiagnosed ARFID in 2021 (2), and twenty-six-year-old Owen Hinds died of complications of ARFID in 2020 (3).

While we recognise that each case has unique circumstances, the recurrence of these reports suggests systemic gaps in the identification and management of nutritional risk in this population.

As professional committees representing specialist dietitians working in paediatrics, autism and ARFID across the UK, we are increasingly concerned about the risks faced by individuals with selective eating, particularly among autistic people.

We use the term selective eating as a pragmatic term to describe a limited diet mainly driven by factors such as sensory differences, fear related to eating, or low interest in food, rather than food poverty, cultural or religious choices, medical needs, body image concerns, or physical difficulty. This includes both moderate selective eating (sometimes called “picky eating”) and more severe presentations, including ARFID.

Our members report a growing number of children and adults presenting with complications of malnutrition secondary to unmanaged selective eating. Conditions such as scurvy (vitamin C deficiency), previously rare in otherwise healthy populations, are now being observed with increasing frequency. Recent case reports have also described nutritional blindness caused by vitamin A deficiency in children in England (4,5).

One parent of a child with ARFID shared with us: *“I knew my child was struggling long before crisis point, but we were repeatedly dismissed. By the time my six-year-old was finally taken seriously, their health had deteriorated so badly that enteral feeding was the only option. No family’s access to ARFID care should depend on where they live.”*

These observations, alongside published reports, suggest the need to better understand how nutritional risk is currently recognised and managed. Potential areas of concern include:

- Challenges in recognising risk in individuals with selective eating, particularly due to micronutrient deficiency being easily missed in the absence of low weight or growth failure
- Variability in access to paediatric and adult dietetic and multidisciplinary support, with this being completely absent in some areas (more so for adults), not just for specialist ARFID services but for general community care.
- Inconsistency in the assessment, management and monitoring of selective eating

Wider system considerations that contribute to variation in care include:

- Lack of comprehensive, cross-age national pathways or service specifications and the need for dietetic provision for identifying and managing nutritional and hydration risk associated with selective eating and ARFID across paediatric, adult, autism and SEND populations in community, acute and primary care settings
- Limited integration across community, mental health, neurodevelopmental and allied health services
- Workforce and financial pressures, alongside increasing clinical demand. The British Dietetic Association (BDA) workforce campaign highlights pressures on the dietetic workforce, including vacancies, recruitment, and retention issues (6).
- Inadequate national data on selective eating and malnutrition prevalence, service provision and outcomes

Our Recommendation

We would welcome NHS England commissioning a national review into nutritional risk associated with selective eating across children and adults.

A review would aim to gain a clearer understanding of systemic failings that need to be addressed to prevent more deaths, blindness, and ill health in individuals with selective eating and inform a coordinated national response.

We suggest that the national review should include consideration of:

- **Prevalence and risk**
    - Prevalence of inadequate dietary intake and micronutrient deficiency
    - Identification of high-risk groups, including autistic individuals
- **Service provision and access**
    - Regional variation in access to dietetic and multidisciplinary services
    - Workforce capacity across dietetics and relevant professions
- **Clinical guidance**
    - Current pathways for selective eating and ARFID
    - Compliance with and gaps in national clinical guidance, including for identification, risk stratification, referral, management, and service

    specification in both general and specialist settings, including special educational needs and disabilities (SEND)

- **Data surveillance**
    - Establishing a national reporting mechanism or registry of preventable cases of malnutrition
- **Wider system considerations, leadership and coordination**
    - Incorporation of eating differences and nutritional risk into the Oliver McGowan Mandatory Training programme for autism and learning disability
    - Explicit consideration of selective eating and associated nutritional risk within the national SEND reforms
    - Opportunities to strengthen integration across services
    - National leadership to support workforce development and training related to selective eating, including prevention and early support access

The deaths of Joshua Allcock, Alfie Nicholls and Owen Hinds highlight the importance of ensuring that systems can recognise and respond effectively to nutritional risk associated with selective eating.

Alfie’s mother told us: “Families should not have to carry the fear, responsibility, and exhaustion of keeping their child alive without the right support. Alfie’s story shows why ARFID needs early intervention and must be recognised and treated before crisis point.”

We respectfully request a formal response and welcome the opportunity to meet with you to discuss next steps.

Yours sincerely,

On behalf of the Committees of the ARFID Specialist Sub-Group, Autism Specialist Sub-Group and Paediatric Specialist Group of the British Dietetic Association:

Sian Taylor
Chair, ARFID Specialist Sub-Group of the British Dietetic Association

Angharad Banner
ARFID Specialist Sub-Group of the British Dietetic Association

Clare Thornton-Wood
ARFID Specialist Sub-Group of the British Dietetic Association

Lisa Holmes
Chair, Autism Specialist Sub-Group of the British Dietetic Association

Zoe Connor
Autism Specialist Sub-Group of the British Dietetic Association

Kiranjit Atwal
Co-Chair, Paediatric Specialist Group of the British Dietetic Association

On behalf of ARFID Awareness UK:

Nicole Kirkland
Co-founder and Trustee, ARFID Awareness UK

Lucy Morrison
ARFID Parent Advocate (Alfie Nicholls ' mother)

Michelle Jacques
ARFID Parent Advocate and Lived Experience Speaker

CC:
Suzanne Rastrick, Chief Allied Health Professions Officer, NHS England
Dr Adrian James, National Medical Director for Mental Health & Neurodiversity, NHS England
Simon Kenny, National Clinical Director, Children & Young People, NHS England

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