A Framework for Good Practice in Delivering Support to Adults and Older Adults with Avoidant Restrictive Food Intake Disorder (ARFID)

Prepared by: NHS England

If you have any questions please contact: england.adultmh@nhs.net

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Introduction

The primary aim of this document is to support local systems to establish and maintain a pathway for Avoidant Restrictive Food Intake Disorder (ARFID) in an adult community eating disorder (AED) service. This framework is primarily for commissioners, service providers, and clinicians of adult eating disorder services (age 18 years and above).

In scope: Community-based adult eating disorder services

Out of scope: Services for children and young people and adult inpatient services.

Community Mental Health Transformation and ARFID

Improving adult eating disorder services is a key priority for NHS England (NHSE) and a fundamental part of our NHS Long Term Plan commitment to expand and improve mental health services.

The NHS Long Term Plan sets out an ambition to give 370,000 adults and older adults with severe mental illness, including eating disorders (ED), greater choice and control over their care and support them to live well in their communities by 2023/24. This includes creating integrated pathways of care across primary care, specialist mental health services, voluntary community sector (VCSE) organisations, and local authority. The Long Term Plan will deliver just under £1 billion of additional funding per year for community mental health by 2023/24.

To support improved ED services, NHSE published national guidance for adult eating disorder services in 2019. Although this guidance covers services for a range of eating disorders - anorexia nervosa, bulimia nervosa, binge eating disorder and other specified feeding and eating disorders (OSFED) - it does not explicitly reference ARFID.

This framework has been developed in response to feedback from clinicians and systems who are keen to better understand ARFID and how to support individuals within transformed community AED services.

What is ARFID?

ARFID is characterised by avoidant or restricted eating behaviours, in the absence of preoccupation with weight and/or shape. ARFID can result from several different causes (and someone may have more than one reason driving their behaviour) e.g.:

- They might be very sensitive to the taste, texture, smell, or appearance of certain types of food, or only able to eat foods at a certain temperature. This can lead to **sensory-based avoidance** or **restriction of intake**.
- They may have had a distressing experience with food, such as choking or vomiting, or experiencing significant abdominal pain. This can cause the person to develop feelings of fear and anxiety around food or eating, and lead to them to avoiding certain foods or textures. Some people may experience more general worries about the consequences of eating that they find hard to put into words and restrict their intake to what they regard as 'safe' foods. Significant levels of fear or worry can lead to avoidance based on **concern about the consequences of eating**.
- In some cases, the person may not recognise that they are hungry in the way that others would, or they may generally have a poor appetite. For them, eating might seem a chore and not something that is enjoyed, resulting in them struggling to eat enough. Such people may have restricted intake because of **low interest in eating**.[1]

Body weight in people with avoidant/restrictive food intake disorder can be in the low, normal or above-normal range. Underweight people with ARFID may present with similar physical health problems related to significant weight loss and malnutrition as those with anorexia nervosa, but clinicians recognise this form of restricted eating behaviour as distinct from anorexia nervosa and needing different treatment[2].

ARFID was first included in Diagnostic and Statistical Manual-5[3] (DSM-5) and is included in International Classification of Diseases-11[4] (ICD-11). Its inclusion resulted from growing evidence about 'atypical' eating disorders. People with ARFID are seen in both child and adolescent and adult services. The diagnostic landscape relating to eating disorders is therefore changing, with anticipated refinements in treatment recommendations as new evidence emerges.

ARFID can be present on its own, or it can co-occur with other conditions; those most commonly co-occurring with ARFID are anxiety disorders, autism, ADHD and a range of medical conditions[5].

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[1] ARFID - Beat (beateatingdisorders.org.uk)
[2] NHS England – CYP Access and Wait Times, 2015
[3] DSM-5 American Psychiatric Association, 2013
[4] ICD11 - WHO, 2019
[5] ARFID - Beat (beateatingdisorders.org.uk)

Principles for delivering community eating disorder services

Optimal model of service delivery for people with an eating disorder is in a dedicated, multidisciplinary eating disorder service, including for people with ARFID. In line with existing guidance, care for individuals with ARFID, should be delivered in the community when it is the most appropriate service to treat the patient's eating difficulties. If care cannot be managed safely in the community then care should be supported by intensive day patient or inpatient treatment for people with a high level of physical or psychiatric risk.

Although current presentations of adults with ARFID may be lower than other eating disorders, there is still a need for services to consider how they could adapt and develop new care pathways to support ARFID presentations, particularly as more presentations are expected as people transition from CYP to adult, due to CYP commissioning arrangements and greater level of awareness. Services should review current service provision and make adaptations based on the resources available. The annexed resources will help services with this process.

Providing treatment for ARFID

Currently ARFID is not included in the NICE guidelines for Eating Disorders, and there is a limited robust evidence base for effective treatment approaches. However, services should seek to get psychological input early, including during the assessment and care planning to help determine the best approach. It is recognised that many interventions used to treat other eating disorders may not be appropriate for people with ARFID due to the different drivers of the condition. However, a mental health professional can support in helping to identify the main contributing and maintaining factors to a person's eating difficulties and the appropriate treatment to tackle the main drivers of food avoidance and restricted eating (e.g. sensory sensitivities, concern about aversive consequences of eating and low interest in food or eating.)

In addition to specific psychological treatments, support must also be provided by a multi-disciplinary team to address other needs including nutritional, physical and mental health co-morbidities.

The list below outlines some potential treatment options which some services are currently using in care pathways for people with ARFID. These treatment options may also be suitable as second line treatments to support with ARFID as a comorbidity. Local systems may not have access to all these treatments, so services should use them as a guide.

Potential treatments and therapies:

- Cognitive Behavioural Therapy (CBT and adapted CBT interventions for ARFID such as CBT-AR)
- Sensory Desensitisation
- Eye Movement Desensitisation and Reprocessing (EMDR)
- Enhanced psychoeducation
- Food chaining
- Food exposure
- Habit acquisition training

How this document was developed

The Adult Mental Health Team at NHS England and Improvement recognised that there is currently limited guidance on supporting adults with ARFID within local systems, including within community eating disorder services. Therefore, building on the work of the Children and Young People's ARFID pilot in 2020, NHSE created a Task and Finish group to inform the work and related materials. This resource was developed with input from clinical professionals, and NHSE Policy Team colleagues from Adult Mental Health, Children and Young People Mental Health, and Learning Disability and Autism Team. Experts by Experience were also consulted.

Annex Contents

Annex one: ARFID checklist

Currently ARFID provision within eating disorder services is limited. This document outlines some key principles that local systems should be following when developing, evaluating, and delivering services for people with ARFID.

Local systems may choose to self-assess themselves against these recommendations and use results to generate actions for service development.

Recommendation	**Recommendation met?** (0 = not in place, 1 = partially met/ plans to implement, 2 = met/ in place)
Focus on co-production – ensure that co-production is embedded within every element from service design to continued delivery	
The ARFID pathway has been developed in collaboration with people with lived experience of ARFID.	
Service users are regularly involved in evaluations and review of the pathway.	
Service user/patient participation are involved in the design of individual treatment packages and delivery of care, ensuring that all care plans are co-produced.	
Peer support services have been expanded to enable service user feedback and co-production on ARFID.	
Children and young people with lived experience of ARFID have been involved in the design of the transition pathway.	
VCSE organisations are consulted with to support co-production.	

Lived experience input is representative of the local population and demographics, especially those who may be most vulnerable to experiencing inequalities and / or struggle with social communication and help seeking behaviours (e.g. those with Autism). This may mean reasonable adjustments are required to ensure barriers to access are avoided and health inequalities reduced.	
Workforce - Ensure the workforce is equipped with the right skills to support people with ARFID	
Appropriately skilled mental health professionals (in line with the competency framework) are involved as part of the assessment and care planning to develop a formulation to inform treatment plans.	
There are resources available to all staff, including staff based in Primary Care, to raise awareness of ARFID and highlight key signs and symptoms.	
Training and education opportunities are provided to staff so they are aware that ARFID could occur alongside other conditions such as autism.	
Staff in eating disorder services have access to specialist consultation from an ARFID specialist.	
Experts by Experience or Peer Support Workers are embedded as part of the workforce to support in the treatment of people with ARFID.	
Links and relationships with other teams and services have been built, so when an ARFID presentation may occur or is further complicated by another condition (eg during pregnancy; gastric problems etc); joined up working is in place to promote quick onward referral processes and access.	

Service design - Consider the needs of people with ARFID in all aspects	
VCSE partners have been engaged to work with people with ARFID e.g. Beat, ARFID Awareness UK.	
Strong links have been built with Primary Care Networks who are likely to be the first point of contact for someone with ARFID, the service provides advice and support on ARFID directly to Primary Care staff when needed.	
The service has or can be redesigned and adapted to help resolve practical challenges which create barriers to service access for people with ARFID, including autistic people and those with co-occurring mental and/or physical health needs e.g. additional training for staff in autism awareness, offering longer appointments, adapting language, adjusting lighting and appointment space.	
Relationships are in place with other systems that already have an established pathway in place to learn from one another and share best practice.	
Outcomes and Practice Based Evidence - Embed the use of outcome measurement and feedback	
Interventions are routinely evaluated for effectiveness e.g. using regular outcome measurements suitable for the specific presentation and gathering feedback from service users.	
Service and population level outcome measures are collected and used systematically to improve quality and safety and reported annually at service review meetings.	
As there is a lack of robust research to inform clinical guidance on effective treatment for ARFID, work with clinicians to review outcomes to help to guide treatment and service delivery.	
Outcome measurements are used to support a person to identify and meet their goals for recovery, recommended outcome measures include Goal-Based Outcomes, ReQoL-10, DIALOG.	
Dietetic services are integrated into a multi-disciplinary team (MDT) to increase positive outcomes.	

Data– ensuring that people with ARFID have equitable access	
Data is collected on the volume and type of clinical need within ARFID services and eating disorder services. This is done by completing scoping work within teams based on presenting needs, not diagnosis.	
Data is collected on the number of people with ARFID who can access the service.	
Data is reviewed with respect to local population and demographics.	
Service user feedback is collected on the interventions being used and this is collated and reviewed regularly.	
people with ARFID are offered the opportunity to be involved in research, service design and service evaluation.	
Clinical governance structures consider the voice of people with ARFID.	
ARFID and autism - ensure that services can support people with co-occurring conditions.	
Individuals with autism are identified, including screening for autism if suspected but not diagnosed, so that communication, support and interventions can be adapted to be autism friendly.	
Services are adapted to support autistic people, for example: - Complete a sensory assessment and sensory interventions - Individualise and co-produce care plan - Adapt dietetic assessments, tools and therapeutic interventions. - Develop a more cognitively concrete and structured approach. - Provider greater use of written and visual information and structured worksheets. - Use simplified cognitive activities, such as multiple-choice worksheets. - Involve a parent or carer in individual therapy sessions. - Consider reducing stimuli in clinic environment, access to sensory box, rocking chairs etc.	
Staff have the skills to work with autistic individuals, as set out in the competence framework for example by offering autism awareness training to staff, and/or additional emotion recognition training to staff. All staff should have undertaken the Oliver McGowen training	
Environmental and delivery changes are made which better support autistic people: - Maintain consistency in appointment times and offer a time slot that meets the needs of the individual. Maintain consistency in location and offer a quite space to wait instead of crowded waiting rooms. - Prepare the individual in advance of treatment starting so they are aware of what to expect.	

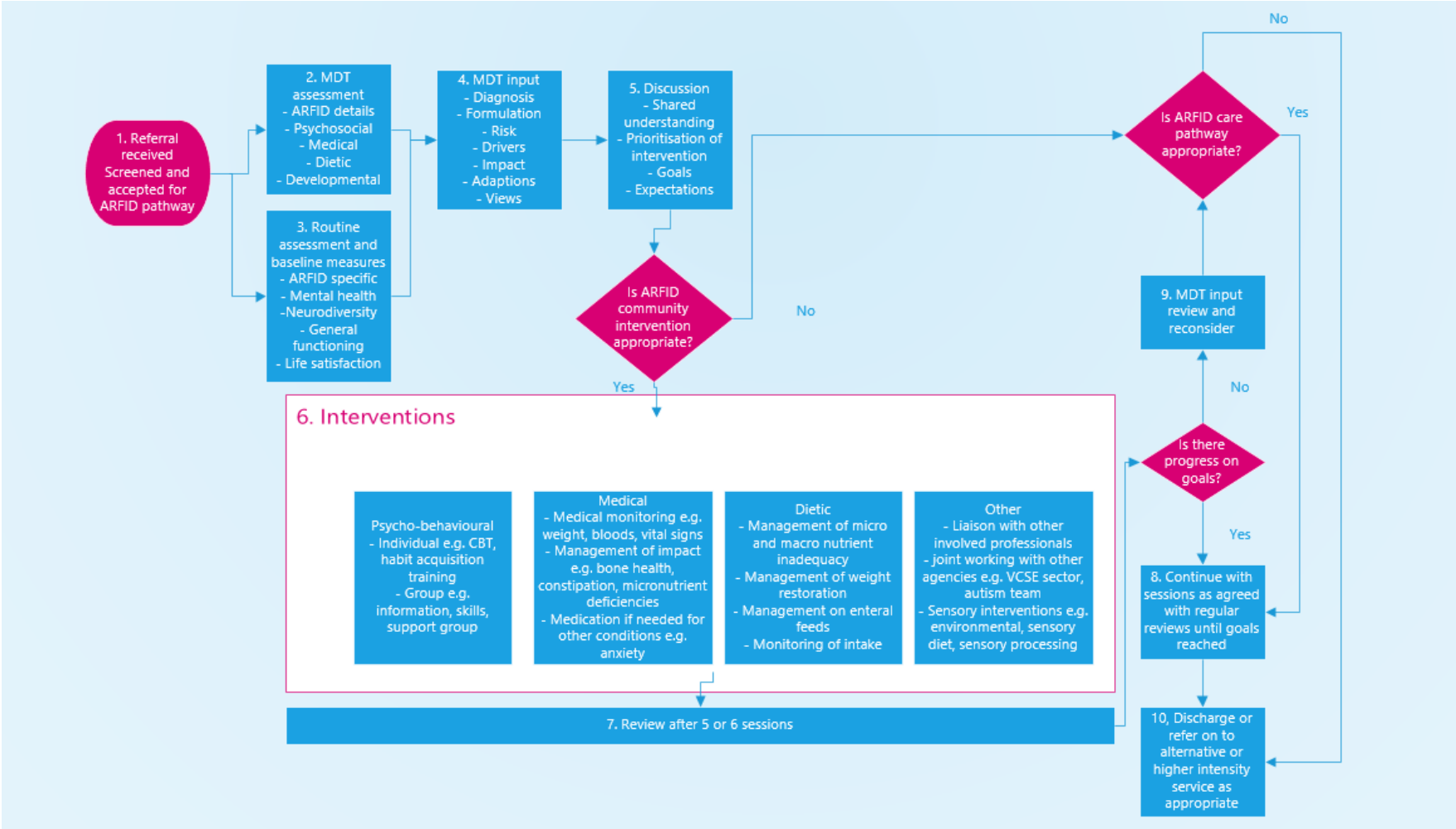
- Incorporate the person's special interests into therapy where possible. - Offer longer appointments. - Provide regular breaks, and consider lighting and noise implications	
Referrals – Emphasis should be placed on removing referral barriers where possible and ensuring ease of access, adapt referral process so services can accept people with ARFID	
Referrals are accepted from specialist mental health clinicians, autism clinicians, Primary Care, as well as self, or VCSE sector referrals.	
All referrals for ARFID are accepted including when there are both physical health and/or psychosocial functioning are within normal range.	
Local referral forms have been adapted to ensure they are effectively screening people for ARFID.	
Any onward referral can be made between services and do not require return to Primary Care.	
Assessment – adapt assessment process to ensure appropriate assessment and diagnosis of ARFID	
Both physical health specialists and mental health professionals, as well as a dietitian are included within the assessment process.	
Additional assessment is provided, involving input from occupational therapists, speech and language therapists, or other specialist clinicians.	
Several diagnostic and screening tools are used and available to service staff: • PARDI AR-Q – The PICA, ARFID, and Rumination Disorder Interview (PARDI) tool which is a semi-structured multi-informant interview that was created to screen for ARFID in both children and adults. • The Nine-Item ARFID Screen for Children and Adults. The nine item ARFID screening tool focuses on emotions and behaviours, rather than weight. It presents nine statements to the individual being tested for ARFID.	
Assessment processes are adapted to identify severity and type of presentation: • Sensory based avoidance or restriction of intake - sensitive to the taste, texture, smell, or appearance of certain types of food, or only able to eat foods at a certain temperature. • Low interest in eating - not recognising hunger in the way that others would, eating might seem a chore and not something that is enjoyed.	

• Avoidance based on trauma – the person may have had a distressing experience with food, such as choking or vomiting, or may have experienced significant abdominal pain.	
Care Planning - Once a diagnosis has been confirmed there are several areas of consideration on treatment approach	
The proposed care pathway could follow the proposed steps below: • Appointment one (75-90mins): MDT assessment to determine risk and treatment pathway. Consider completing full medical and pharmaceutical review, psychological assessment, dietetic assessment • Appointment two: occupational therapy assessment if needed • Appointment three: begin therapy and treatment (see section below)	
However, all services are designed differently and therefore may have limited access to certain resources, therefore the key things to consider include: • Ensure discussion takes place between the person and potential family members or carers on the diagnosis and treatment options. • Ensure discussion takes place between the MDT and arrive at a shared understanding of the presentation. • Reach agreement on potential targets and treatment goals, based on desired behavioural change goals for people with ARFID. • Working with the individual identify any other areas of impact that they wish to work on. • Set expectations regarding extent and pace of change and length of treatment. • Care must be coordinated with other services to reduce and prevent gaps in care during service transitions (age-related, geographical, community to inpatient transitions). • Put in place clear protocols and joint working agreements with services, including autism services, gastroenterologists.	

Treatment - The main objective of treatment for ARFID is to achieve lasting changes in eating behaviour, through reducing the frequency, extent and impact of avoidance or restriction of food intake.	
A range of therapy and intervention options are available, including: - Cognitive Behavioural Therapy (CBT and adapted CBT interventions for ARFID such as CBT-AR) - Sensory Desensitisation - Behavioural Therapy - EMDR - Enhanced psychoeducation - Food chaining - Food exposure - Other relevant interventions determined by psychological input	
NICE does not recommend medication as the sole treatment for any eating disorder. However, medication is considered medication for related problems, e.g. anxiety or another co-occurring problem, where appropriate.	
Support is provided for the physical health of somebody with ARFID (e.g. bone health, constipation, micro-nutrient deficiencies).	
Arrangements are in place for ongoing medical monitoring (weight, growth, bloods, vital signs etc). More information is available in this guidance.	
Regular dietetic input is available to provide advice and treatment on: - Management of micro- and macro nutrient inadequacies - Management of weight restoration - Management on enteral feeds - Oversight and monitoring of food and fluid intake.	
Other interventions are considered on an individual basis and delivered simultaneously as part of a multi-modal approach.	
Length of therapy and interventions are delivered over a longer period.	
Services are redesigned to meet the needs of people with ARFID, especially at the start of treatment for example by offering shorter but more frequent appointments.	

Reviewing progress - Reviewing progress and adapting of treatment and intervention method is needed on a regular basis.	
Regular reviews take place to ensure treatment remains focused on the established shared goals, these could include: - Identify any barriers to change and consider whether alternative interventions may be needed. - Review whether there are any factors hindering progress e.g. an unexpected change in a circumstance such as financial or health difficulties. - The rate of progress might need to be reconsidered and revised in relation to other aspects of the presentation, for example the presence of disability or autism. - Engage with the multi-disciplinary team to review the treatment plan.	
Procedures and protocols are in place to provide additional investigation or onward referral if needed	
Local discharge protocols have been adapted to ensure the individual with ARFID feels prepared and supported to leave the care of specialist services.	
A detailed discharge plan is provided which outlines support on relapse prevention, to enable the person, other health professionals, GPs, families etc to respond early. This should also include sufficient information about the support which the individual has received and outcome details.	

Annex two: example care pathway[6]



[6] Bryant-Waugh et al, 2021

Annex three: case studies

Kindly provided by Yorkshire and the Humber Clinical Network

ARFID case study one

Mark is a 26-year-old male, who lives with his wife and new baby. Mark has not sought help for his eating problems previously, however, his issues have reached crisis point, as his wife needs his support with weaning with their 6-month-old son.

Mark has had a significantly restrictive diet since he was a baby. Throughout his childhood, he demonstrated significant distress associated with certain foods, eating and being around others when eating. Whilst a baby and toddler, his mum was really concerned, and food and mealtimes became a source of anxiety for the whole family. Mum sought help and was encouraged to give vitamin supplements and see Mark's eating distress as 'attention seeking' and to implement positive reinforcement strategies using a behavioural star chart approach to encourage Mark to be rewarded when eating meals with the family. This achieved limited to no success.

Mark is now within the normal healthy weight range, but still has significant vitamin and mineral deficiencies, which he takes supplements for. He has never been out to eat with his wife, and his eating issues significantly impacts on family occasions and holidays. He fears all new foods and his last attempt to prepare food for his wife when she was ill left him shaking and crying on the doorstep, as he was unable to do it. He carries significant fear, shame and disgust at his inability to "just eat". Mark is desperate for help.

Mark's diet:

- Dry cornflakes. Heinz chicken soup (brand-specific) and white bread. Chocolate flavoured yogurt- one brand only.
- Chicken nuggets and chips- another chocolate yogurt. McDonalds is ok.
- Occasionally a chocolate biscuit or a sweet. No fruit or vegetables and no other food options.
- He takes a range of prescribed supplements to prevent vitamin deficiencies.

Assessment

Mark presents with significant sensory processing difficulties in relation to taste, texture, smell and struggles with the sound of others eating. His eating issues are inextricably linked to his anxiety and fears. Due to poor nutritional diet, bloods (FBC / TFT) were also requested.

Formulation and Plan.

Mark completed a detailed sensory assessment with a psychologist and completed a diary of associated thoughts and feelings. Mark also saw a dietitian who completed a

detailed dietetic and nutritional analysis of his food intake. The diagnosis of ARFID was explained, both alleviating blame and enhancing self-efficacy.

Diet:

- Dry cornflakes. Heinz chicken soup (brand-specific) and white bread. Chocolate flavoured yogurt- one brand only.
- Chicken nuggets and chips- another chocolate yogurt. McDonalds is ok.
- Occasionally a chocolate biscuit or a sweet. No fruit or vegetables and no other food options.
- He takes a range of prescribed supplements to prevent vitamin deficiencies.

The treatment plan focused on anxiety management and sensory regulation. Mark recognised when keeping a diary that he has a learned predictive negative association with all things that are eating, and food related, and he recognises that his associated elevated anxiety has become 'hard wired'.

Mark receives psychoeducation around his sensory sensitivities and anxiety management and collaboratively works on steps involved in graded exposure work (SOS style). Mark is now able to regulate his affect more effectively as he can eliminate other sensory stimuli whilst focusing on food and eating to maintain an optimal window of tolerance (e.g. choosing a quiet time, turning off phones, opening windows to reduce smells etc). This then enables Mark to focus on one task. Marks wife was included in the treatment plan and together they found a quite time of day outside meals to do some graded exposure. Mark identified his first steps, by listing foods similar to those already eaten and combining with food chaining principles. Mark found it helpful to start exposing himself to pictures of the new foods, this was stepped up to placing the food on his hands. Linking foods with positive and soothing associations was important in deconditioning. Mark found playing music he liked helped both with deconditioning but also as a distraction from the sounds of others eating. Mark was then able to step up the exposure to smelling and bringing the food to the mouth, but not consuming. Finally, Mark was able to try new foods. Mark used cognitive predictions and assessed against his experience of the food exposure.

Further to this input, Mark now has significant autonomy over his eating and his ability to try novel eating situations. He is comfortable eating with his wife and son and enjoys seeking fun ways with his son to try new foods together.

ARFID case study two

Elaine is in her 70's. She has had a restricted diet all her life and is underweight with osteoporosis and heart failure. Elaine fears vomiting if she eats too much or eats certain foods. She has stated a mindfulness course and wants to try and focus on her eating.

Over the years Health Care Professionals have not understood Elaine's condition and she has been labelled as 'weird' and 'fussy' around food. She has tooth abscesses and some teeth have fallen out due to malnutrition. Her bones ache and she is tired. Elaine avoids any foods that she labels 'too solid'. This stems from seeing her brother choking on a carrot stick when he was 5 years old that he didn't properly chew because he had to eat it, before being allowed to have his sweet. Elaine remembers him stopping breathing and her parents screaming and shouting whilst slapping his back and tipping him upside down. The carrot eventually flew through the air, but Elaine was left paralyzed with fear and committing herself to never eat a vegetable again. Her portions are extremely restricted, and all the foods, she was willing to eat, had to meet her criteria of 'not too solid'. This was a very idiosyncratic criteria e.g. 'not too solid' included cake, chips and 'too solid' included cheese, foods with lumps – like stew. Elaine eats around half the calories she needs, and any change in routine results in her not eating at all. She feels tired and she knows her body is struggling. She wonders if it is too late to change. She has never heard of ARFID and did not realise it could be treated.

Assessment

Elaine was referred to a dietitian and psychologist and she was immediately started on a multivitamin and Vitamin D. She completed a detailed sensory profiling assessment.

Formulation and Plan

Elaine was offered a detailed explanation of ARFID which enabled her to understand and feel validated. Elaine wanted to get started herself and she was signposted to the CBT-AR book, as a resource.

Elaine focused on her anxiety and psychoeducation on interoceptive signalling and feedback loops. Elaine was able to understand that many of her food choices were objectively similar in both groups, but many she was selecting due to a sensory preference or a predictive bias. Elaine was also able to recognise inconsistencies, e.g. she would not eat any vegetables but could eat chips. The dietitian prescribed meal portions in a graded way to working towards e.g. 2 Weetabix and 150ml milk. She was also offered sip -feeds by her dietitian. She has been able to eat pureed vegetables.

Elaine's psychologist focused on CBT work around graded exposure/possibility/probability e.g. "I can tolerate this sensation and I won't choke "vs "I can't tolerate this sensation and I will choke". Elaine found this helpful allowing an ability to have greater psychological flexibility around these previous rigid thoughts and beliefs. Elaine was encouraged to bring some fun in creating some

behavioural experiments when testing her predictions around trying new foods and choking. Elaine continued to notice cognitive traps /avoidant behaviours and building up portions/tolerance with new foods.

Elaine now has more balanced eating plan and has lots of autonomy and self confidence in adding and trying new and additional foods to her diet. She does remain frustrated that she wishes she had received help earlier.

Annex four: useful links and resources

We have created a space on FutureNHS which brings together information and resources on ARFID, and where services can ask questions via the community eating disorders discussion board. Please check this space for latest resources and case studies Future NHS

Adult Eating Disorders: Community, Inpatient and Intensive Day Patient Care: Guidance for commissioners and providers (england.nhs.uk)

Access and Waiting Time Standard for Children and Young People with an Eating Disorder: Commissioning Guide

ARFID Awareness UK

ARFID - Beat (beateatingdisorders.org.uk)

PEACE Pathway - About PEACE