Spectrum
Community Health CIC

Food refusal toolkit

Welcome to the food refusal toolkit!

The purpose of this toolkit is to equip you with clear, accessible and practical information in managing cases of food refusal in secure estates.

For any concerns, questions or comments please contact Spectrum Community Health CIC's Safeguarding Team:

SafeguardingTeam@Spectrum-cic.nhs.uk

Disclaimer

This toolkit has been developed as a resource for healthcare staff within secure settings who are working with individuals who may refuse food. It has been produced in line with Spectrum Community Health CIC's Food Refusal Policy, as well as resources and guidance from NICE, the Department of Health and the Mental Capacity Act Code of Practice. It is not intended to replace individualised care planning and should be used as a guide only.

Contents

- What is Food Refusal? 04
- Risks of Refusing Food and Fluids 05
- Making Safeguarding Personal 07
- Communication and Assessment 09
- Mental Capacity 12
- Assessment of Mental Capacity 14
- Mental Health 17
- Executive Function 19
- Best Interests Decisions 20
- Physical Observations 23
- Refeeding 25
- Multi-Disciplinary Team Meetings 29
- Care Planning and Documentation 34
- Roles, Responsibilities and Escalation 36
- Dealing with Challenge 39
- Process Flow Chart 40
- Process: Food Refusal for 3 Days or More 41
- Further Support and Resources 43

What is Food Refusal?

Food refusal is when a person refuses to eat. This can be for a variety of reasons.

Some patients refuse to eat as a protest, it may be a decision they have made to prompt a specific result or response.

Others may be experiencing physical or mental illness, for example psychoses, severe depression, drug induced psychosis, or dementia.

In each case an **individual assessment** is required to establish the facts, causes or purpose of the behaviour.

Risks of Refusing Food or Fluids

Refusing food has different physical consequences to refusing fluids.

Fluid refusal for more than 24 hours becomes a medical emergency. Anyone whose fluid intake is less than 500ml in 24 hours should be reviewed as a matter of urgency. The Food Refusal Policy contains a flow chart for managing cases of fluid refusal *(Appendix 2)*

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Food refusal leads to malnutrition and has significant impact on organs, muscles, and changes in cell function, including depletion of specific electrolytes, minerals, and micronutrients, some of which can lead to serious illness and death.

Some patients may be at higher risk of serious consequences of food refusal depending on their current health.

Even patients who are overweight or obese are at risk of these complications.

Food refusal is a form of self-neglect and comes under the umbrella of safeguarding adults when commenced by an adult with additional needs or risks. If in doubt, contact Spectrum Community Health CIC's Safeguarding Team:

SafeguardingTeam@Spectrum-cic.nhs.uk

Making Safeguarding Personal

Adults who have full mental capacity have the right to make choices which others view as unwise. This includes making decisions to refuse healthcare treatment, and to refuse to eat or drink.

'Making Safeguarding personal' is the underlying principle in adult safeguarding, emphasising a person's individuality and right of choice.

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The complexity arises in a healthcare setting where we have a duty of care towards our patients. Working with someone who is making a decision to refuse food or fluids in a healthcare setting is extremely challenging.

Food refusal is considered as a form of self-neglect and may come within a safeguarding remit if the individual has care and support needs or additional vulnerabilities.

The key is to keep the wishes, views and feelings of the individual at the forefront of all decision making and interventions and ensure this is reflected in all documentation.

Communication and Assessment

Engaging and communicating with the patient is key in assessing and understanding why someone may be refusing food.

- Is English the patients first language? Is their grasp of English enough to hold conversations around complex health issues, or is an interpreter needed?
- Does the patient have any learning needs?
- Do they require information in a different format?

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- Does the patient have any sensory impairment such as hearing/vision related issues?
- Is their current mental state/physical health issue impacting on their ability to communicate?
- Does the patient have a physical issue preventing eating, such as swallowing issues, infection, oral issues, pain, or other physical concerns?
- Speak to the patient about their thoughts, concerns, the reasons they are refusing food. Can the issue be resolved?
- Provide the patient with written information on the consequences and risks of refusing food *(Appendix 4, Food Refusal Policy)*

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- Communicate with other staff on site, partners, prison staff and build a picture of what is happening for the patient
- Communicate with the patient's family and/or advocate should they consent to this
- Discuss in site safety huddles to raise awareness of the issue amongst staff
- Seek advice and support if needed from Spectrum's Safeguarding Team
- Submit a DATIX

Mental Capacity

When a patient is refusing food or fluids it is essential to consider whether they have the mental capacity to make this decision.

If there is any reason to suspect that someone's mental capacity is impaired, then a full mental capacity assessment must be completed.

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Factors which may impact on mental capacity include (but are not limited to):

- Learning difficulties
- Autistic Spectrum Disorders
- Dementia
- Temporary loss of memory
- Head or brain injury
- Physical illness
- Mental health issues such as psychosis, depression, bipolar disorder
- Eating disorder
- Known personality disorder or history of self-harm
- History of substance misuse

Assessment of Mental Capacity

The assessment of capacity is to establish whether someone has the capacity to make a **specific** decision at the **time** it needs to be made.

The 2-Stage Test

The starting assumption is always that the person has capacity to make the decision. **However, care must be taken not to discount unwise decisions as simply a person having the right to make them.** A person's condition, (for example addiction) may impact on their decision making. (See '*Executive Function*' section).

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Stage 1

Is the person unable to make a specific decision when they need to?

They are deemed unable to make a decision if they cannot:

- Understand the relevant information through any means
- Retain the information long enough to make the decision
- Weigh up the information in making the decision and consider the consequences
- Be able to communicate the decision (could be via non-verbal gestures, visual aids etc).

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Stage 2

If unable to complete the functional test above, is this due to an impairment of the mind or brain, **or** is there a disturbance affecting how their mind or brain works?

The Mental Capacity Act Policy contains further guidance and an example template to assist with completing capacity assessments.

It is important to document in the patient's records how you have arrived at your conclusion, for example, evidence and rationale for the decision reached using the above points as a guide.

Mental Health

A person might be refusing food due to a mental health issue. In these cases, we need to be as confident as possible that their decision making is not impacted by their symptoms. Any known impact of mental illness as described below should lead to us questioning mental capacity.

Psychosis

Symptoms of psychosis such as paranoia, delusional beliefs, or hallucinations may lead to a person refusing food.

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Depression

People with depression may be experiencing suicidal ideation so the food refusal could be an attempt at self-harm/suicide.

Bipolar

Decision making may be impaired in patients who are experiencing mania or low mood.

Personality Disorders

Patients with personality disorders can present with complex behaviours and disordered thinking. We would need to consider mental capacity in these patients when they are refusing food.

Other mental health issues may also impact on mental capacity. As a general rule, any person with mental health concerns, whatever the cause, has the potential to be experiencing impact on their capacity to make an informed decision.

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Executive Function

At times it may be necessary for us to delve deeper beneath what people say when considering mental capacity. The person may appear to ‘talk the talk’ (decisional capacity) but may in practice be unable to ‘walk the walk’ (executive capacity).

Example: when an underlying mental health issue is impacting upon actions or decision making, or when a person is addicted to substances and this addiction impacts on their decisions.

Complex issues such as this would require an MDT discussion and may lead to a Best Interests meeting being held.

Best Interests Decisions

Any decisions made on behalf of a person, who is deemed not to have the capacity to make the decision themselves, must be made in the person's Best Interests. This is a legal requirement of the Mental Capacity Act.

Best Interests Checklist:

- Do not discriminate or make judgements due to age, appearance, or condition
- Consider all relevant circumstances
- Involve the person
- Consider any previous wishes or feelings, e.g. an advanced decision
- Consult as far and widely as possible

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When it has been established that a person does not have capacity to make a specific decision, and that this is putting the person at risk, then a Best Interests (BI) Meeting should be held.

The following principles should be adhered to:

- The person must be central to the decision-making process
- Cultural issues and beliefs must be considered
- We must consult with family or friends, if appropriate

The BI meeting should include all those who would be invited to the MDT as described above.

In addition, a family member should be invited to take part (if appropriate and applicable). In the absence of a family member or other who can represent the voice of the person, a referral must be made to the **Local Authority Independent Mental Capacity Advocate (IMCA) Service.**

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IMCA's are a legal safeguard for people who lack the capacity to make specific decisions such as accepting medical treatment.

If a BI meeting needs to be held before the IMCA can be involved, then a referral must still be made, and this must be documented in the person's health records. Family views must be included wherever possible.

A BI meeting enables robust consideration of the risks, options, and development of a plan. **Complex decisions made in this arena are made with joint responsibility of all who attend.**

For complex cases, the Legal Team should be invited as there may be a need to make an application to the Court of Protection for a Judge to make the final decision on what actions would be in the best interests of the person.

Physical Observations

For patients who have refused food for more than 3 days:

- ✓ Baseline BMI
- ✓ NEWS 2
- ✓ Review medications
- ✓ Baseline bloods to include FBC, urea and electrolytes, glucose, liver function, magnesium and calcium, phosphate, c-reactive protein and erythrocyte sedimentation rate.

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Ongoing Investigations:

- Daily NEWS 2 (or as indicated by score)
- Weekly bloods as above
- Review weight/BMI as required

For Patients who have refused fluids or intake is less than 500ml in 24 hours:

- Arrange a medical assessment
- Maintain fluid balance chart
- NEWS2 four times per day
- Daily bloods: FBC, U&E, magnesium, phosphate, calcium
- Daily urine: ketones

For patients with mental capacity, request the patient signs a disclaimer when they decline physical observations or treatment (Page 9 - Food Refusal Policy)

Refeeding

Refeeding syndrome

Describes a range of life-threatening biochemical and clinical abnormalities occurring when food is given to starving individuals.

These can include cardiac failure, acute circulatory fluid overload and fatal production of phosphates, magnesium, and potassium as well as liver dysfunction and hypoglycaemia.

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Wernicke-Korsakoff Syndrome

Occurs due to increased thiamine demand as starving cells return to carbohydrate metabolism. It is seen more frequently in alcoholics who have lower liver stores of thiamine but can occur in a starved individual who recommences eating.

Due to these risks, any re-introduction of nutrition must be carefully controlled and monitored.

Reviewing Risk of Refeeding

People who have not eaten for less than 5 days with BMI > 18.5kg/m2 are at little or no risk (negligible risk).

Moderate Risk:

- BMI less than 18.5
- Have lost more than 10% of their body weight since refusing food
- Have had little or no food intake for between 5 and 10 days

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High Risk (major risk factors):

- BMI less than 16
- Weight loss greater than 15% of body weight since refusing food
- Little or no nutritional intake for more than 10 days
- Low levels of potassium, phosphate or magnesium prior to refeeding

Only one of the above risks is required to be considered high risk.

High Risk (lesser risk factors):

- BMI less than 18.5
- Weight loss greater than 10%
- Little or no nutritional intake for more than 5 days
- History of substance misuse or use of insulin, chemotherapy, antacids or diuretics

Two or more of the above risk factors would be considered high risk.

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Extreme Risk:

- BMI less than 16kg
- Weight loss greater than 15% of body weight
- Little or no nutritional intake for more than 10 days
- Low levels of potassium, phosphate, or magnesium prior to refeeding
- History of substance abuse or use of insulin, chemotherapy, antacids or diuretics
- Significant comorbidity or infection, high or low blood glucose levels

More than one of the above risk factors would be considered extreme risk

Those identified as being at high or extreme risk of refeeding require care from professionals who have expert knowledge in nutritional support. As described in the NICE guidelines on refeeding, these high-risk patients must be admitted into hospital to be appropriately treated and monitored.

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Multi-Disciplinary Team Meetings (MDTs)

MDTs allow for **shared decision making and responsibility**, robust **action planning** and **escalation** of cases which are potentially complex.

Professionals from different disciplines with a variety of expertise can pool their knowledge and resources to support sites and ensure the best outcome for service users.

MDTs offer a source of support for sites in managing risk and provide an additional layer of governance.

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Sites should consider planning an MDT when one or more of the following apply:

- A patient has refused food for 3 days
- A patient has begun to refuse fluids
- A patient has complex physical or mental health needs and is refusing food
- There are concerns that any patient, with or without mental capacity is putting themselves at significant clinical risk by refusing food or fluids
- When a patient would be at risk of ‘refeeding’ syndrome
- If a patient is refusing physical observations whilst refusing food or fluids

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MDTs should be planned and coordinated by staff on site. They should include the following as a minimum:

- Head of Healthcare or another senior member of staff who knows the patient
- The on-site GP who knows the patient
- Mental health professionals (if involved)
- The Safeguarding Link Practitioner on site (if available)
- A representative from Spectrum's Safeguarding Team

It may also be appropriate to invite other partners or professionals working with the patient, such as:

- Prison staff/Safer Custody
- Social Care Staff
- The Regional Lead GP
- Other professionals such as Speech Therapists, Occupational Therapists

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- External partners such as staff from acute NHS Trusts/hospitals
- External mental health providers
- Representatives from the Legal Team (for complex cases)

Where appropriate, Cluster Managers can also be invited to MDTs when cases require escalation.

It is important that the voice/wishes/feelings of the patient are heard within the MDT. This may be by facilitating the patient to attend if appropriate, or having their views represented via a family member or advocate.

Roles and Responsibilities in MDTs

The most senior member of staff on site in the MDT will be responsible for chairing the meeting. Notes/minutes must also be taken either by the Chair, or another member of staff on site.

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It is up to staff on site to ensure that the notes from the meeting are documented in the patient record to include:

- ✓ Who attended (name and role)
- ✓ Points of discussion
- ✓ Any areas of challenge/concern
- ✓ A clear action plan stating who is responsible for each action and a timescale for action completion
- ✓ Details of any further planned meetings

Care Planning and Documentation

Everyone commencing food/fluid refusal must be placed on a Food and/or fluid refusal care plan.

Documentation should reflect that all aspects within this toolkit have been considered. Records should evidence:

- Exploration of the reasons for the food or fluid refusal and any attempts made to resolve them
- Clear reference to mental capacity, whether the patient is deemed to have this or not
- A completed Mental Capacity Assessment template (if applicable)

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- Evidence of discussion with others, for example colleagues, partners, heads of service or external colleagues and the outcomes of these
- Physical observations and results
- Ongoing attempts to engage the patient
- Any rationale for decisions made and details of advice sought
- Clear documentation re MDTs as described above
- All records should include regularly reviewed plans and outcomes of actions
- The patient voice, views, wishes, feelings
- The physical presentation and condition of the patient

Remember, documentation in patient records will form part of any legal evidence should the worst-case scenario happen. We need to ensure all our good work is captured appropriately.

Roles, Responsibilities & Escalation

It's important to ensure complex cases have been handed over and that plans are in place for on-call staff at weekends and Bank Holidays.

All staff on site have responsibility in recognising and escalating cases of food or fluid refusal. This includes recording and documenting concerns, seeking further support, and initiating the food refusal care plan.

Heads of Service are responsible for ensuring policies and processes are embedded and that

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staff are working in line with these. They will also plan or delegate planning of MDTs when required and will lead or oversee this process, including ensuring the documentation is clear on the patient records.

Safeguarding Link Practitioners in sites are able to offer additional guidance and support if required.

GPs on site are responsible for ensuring medical interventions are in line with the Food Refusal Policy and in reviewing and providing a clinical opinion on the current physical health risks/status if known. They may also be required to liaise with medical colleagues in acute hospitals or partner agencies if needed.

Spectrum Safeguarding Team will provide support to all staff. This will include one to one advice, case discussion, attending MDTs or BI meetings, advising around documentation as well as advice on negotiating complexities of the Mental Capacity Act.

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Cluster Managers will provide advice and support for cases which are escalated due to the level of risk.

The Director of Nursing, Director of Operations and Associate Medical Director can provide support as required at the point of further escalation.

Complex cases involving aspects of the law, such as the Mental Capacity Act, can be escalated to the **Legal Team** for any advice or support. The Safeguarding Team can provide links to this service.

Any potentially serious incidents would be escalated with agreement to the **Chief Executive** of Spectrum.

At times we are required to escalate cases of concern to **Commissioners** in NHS England and to the **CQC**.

Dealing with Challenge

Healthy challenge and professional disagreement can be useful when we are managing complex cases as it allows us to consider several viewpoints and ensure the best outcome for the patient.

However, where issues cannot be resolved and disagreement and challenge are hindering the process, staff can seek advice and support.

The Safeguarding Team can support when there is a difference of opinion by facilitating a positive discussion to establish common ground and try to move forward with an agreed plan.

Process Flow Chart – First Steps

Staff identify a patient not accepting food or fluids

Consider Mental Capacity and Mental Health. Complete a Mental Capacity Assessment if required. Consider referral to Mental Health team

Establish reasons, causes. Communicate, support and signpost. Consider an ACCT. Arrange internal MDT and submit DATIX

Inform Wing Manager and Oscar 1. Inform Healthcare and document on record. Commence food/fluid refusal monitoring sheet

If the patient has capacity, provide them with information on Advanced Decisions and the Information Leaflet

Commence food/fluid refusal care plan. Complete clinical assessment including NEWS2 and bloods. Review MIPRA meds. Make a GP appt for further clinical assessment

Discuss with Safeguarding Team

Consider healthcare admission

Process: Food Refusal for 3 Days or More

- Encourage Patient to eat and explore reasons for not eating
- Check communication
- Assess capacity to make the decision to refuse food. If no capacity, follow the MCA procedure
- Arrange a medical assessment
- Arrange an MDT meeting and continue weekly

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- Submit a DATIX and a prison incident form
- Consider an ACCT
- Consider referral to Mental Health Team
- Maintain food refusal log
- Place patient on fluid refusal ledger on S1
- Implement food refusal care plan
- Inform Oscar 1
- Monitor NEWS2 daily
- Take height and weight including BMI
- Weekly bloods – FBC, U&E, magnesium, phosphate, calcium
- Review meds and MIPRA
- Consider Dietician referral

Follow the above until either the patient commences eating or is transferred to hospital for re-feeding

(Adapted from Spectrum Food Refusal Policy)

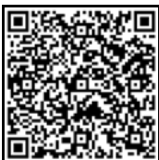
Further Support and Resources

Spectrum Safeguarding Team:
Safeguardingteam@spectrum-cic.nhs.uk

Spectrum Policies available via the Intranet:

- Food Refusal Policy
- Mental Capacity Act Policy
- Safeguarding Adults Policy

Other Resources and guidance:



Mental Capacity Act
Code of Practice, 2005

HM Government, 2019:
DSO 03/2017; Care and management of detained individuals refusing food and/or fluid

NICE 2010
Guidelines for the clinical management of people refusing food in IRCs and prisons

This Toolkit was developed by Donna Phillips, Named Nurse for Safeguarding, Spectrum Community Health CIC, as part of an NHS England funded project.