



***Guidelines for the clinical
management of people
refusing food in immigration
removal centres and prisons***

Guidelines for the clinical management of people refusing food in immigration removal centres and prisons

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1 Executive summary

There has been a long history of protest or planned suicide through food and sometimes fluid refusal in all kinds of detention settings throughout the world, and deaths of prisoners or detainees have occurred. This document aims to provide health professionals in prisons and immigration removal centres with information on the legal aspects of such practices, the physical effects of food and fluid refusal, and the most effective practical and clinical management of individuals refusing to eat or drink. It also addresses the risks of refeeding, which are considerable in individuals who have been starving but who then decide to eat again.

Many of the recommendations are drawn from expert opinions expressed in 2006 NICE guidelines on nutrition support in adults, modified to take account of the different care setting and the fact that prisoners or detainees may not be otherwise unwell.

Guidance on the right to refuse food and/or treatment was previously specific to prisons. However, the Mental Capacity Act 2005 made guidance applicable to all settings. Any individual has the legal right to refuse food and fluid. The Act states that a person is assumed to have capacity unless it is established that they lack capacity and must not be considered unable to make a decision merely because they make an unwise decision. Sections 24 to 26 of the Mental Capacity Act 2005 cover “advance decisions” to refuse any type of treatment. The key characteristics of just such an advance decision are set out clearly in the Act (Appendix 2).

This document sets out the signs and symptoms of malnutrition and the effects of starvation. It also covers the identification, assessment and management of a prisoner or detainee who is intent on refusing food and, if appropriate, on recommencing eating and drinking. Management includes establishing the primary reason for food refusal and if possible finding ways to ameliorate the situation, possibly by initiating case reviews as set out in Prison Service Order 2700, Suicide Prevention and Self-Harm Management. Food or fluid refusal does not mandate the use of an Assessment, Care in Detention and Teamwork (ACDT) or an Assessment, Care in Custody and Teamwork (ACCT) (the assessment and care planning system for at-risk detainees or prisoners). However, it will be appropriate in the case of prisoners or detainees refusing to eat and/or drink fluids to open an ACCT or ACDT plan, where the prisoner/detainee is identified as requiring special care due to the potential risk of suicide or self-harm. Where an ACCT/ACDT is raised there is a

requirement to ensure that relevant and appropriate information is transferred to the document by healthcare staff. It is important to explain the staff's desire to keep the individual as well as possible during the period of food refusal. The aim is to identify how best to resolve the situation by developing strategies for psychological, physical and social well-being. It is also important to identify how the individual wishes to be managed clinically if the situation cannot be resolved satisfactorily. Clinical staff must ensure that the individual understands and retains information, particularly the seriousness of refusing food and later refusing life-supporting treatment. Clinical staff will support the individual throughout the process feeding back to the individual throughout their time in custody.

The starting assumption must always be that a person has the capacity to make a decision, unless it can be established that they lack capacity.

Any lack of mental capacity and/or the presence of mental illness must be identified as this may invalidate any advance decision. If the clinician has any concerns, the patient must be referred to a psychiatrist for a mental health assessment and assessment of capacity. Assessment of capacity is a two-stage test. Does the person have an impairment of brain or mind? If so, does the impairment make the person unable to make the decision in question at the time it needs to be made? The Mental Capacity Act 2005 Code of Practice describes the assessment of capacity and advance decisions and should be read in conjunction with this document.

A thorough assessment of nutritional status should be undertaken at the outset of the fast, including establishing levels of recent food intake and usual body weight and performing a specific nutritional examination. Regular reassessments of a food-refusing individual's physical and mental state should be undertaken within limits dictated by the individual's compliance. Soon after an individual is identified as embarking on a period of refusing food, a case conference should be considered to explore further any ameliorating factors and assist care planning.

Full documentation of the individual's wishes is essential to demonstrate that the individual is not only refusing all forms of feeding but understands the likely consequences of doing so. Additionally there should be a written account of how the individual wishes to be managed and ideally an advance decision prepared jointly with the individual. Such management is endorsed by the Ministry of Justice Legal Directorate and should include a statement that this applies to refusing life-sustaining treatment of food and fluid replacement at any stage during a fast. The advance decision should be signed by the individual in the presence of two witnesses, who also sign.

An individual who decides to recommence eating after refusing food for more than a few days is at potential risk of refeeding syndrome, especially if they were malnourished at the outset. This guidance emphasises that no hard evidence exists to guide practice, but refeeding syndrome can be fatal and hence caution is needed. It advises on degrees of risk and provides guidance on reintroducing food relative to the risk category. In extreme cases, this may entail tightly controlled reintroduction of nutrients with careful physical and biochemical monitoring in a hospital setting.

Individuals at modest, high or extreme risk from refeeding syndrome should have their management discussed with a clinical nutritionist or a hospital specialist team at the end of a fast. Hospital admission may well be the most reliable way to institute refeeding for these individuals so that their clinical state, including temperature, blood pressure, respiration rate, body weight, fluid balance and biochemistry, can be rigorously monitored while controlled dietary intake and adequate vitamin and electrolyte supplements are started.

For the prisoner or detainee continuing to refuse food or fluids, following discussions with hospital specialists, consideration should be given to an assessment in hospital once the person has become weak, dehydrated or probably dehydrated, oedematous, or has developed significant biochemical abnormalities. This could take them out of the situation in which their protest has the greatest relevance, and it brings them into contact with healthcare professionals who have no link with their detention or case. Under these circumstances, it is hoped that they will reconsider their fast and allow rehydration and refeeding to commence. If treatment is refused, the hospital may decide to discharge the individual back to the centre or prison for further management and care.

These guidelines also provide information for the patient on the consequences of food refusal and two flow charts that aim to serve as a synopsis of good practice in assessment and management.

This document does not apply to the management of young people under the age of 18 years, because such young people are outside the remit of the Mental Capacity Act 2005.

2 Background

2.1 Aetiology and prevalence of food refusal

Food refusal as a form of protest is not uncommon in custodial systems throughout the world. However, clinical management within the UK has changed with time. The imprisoned suffragists went on hunger strike and were force-fed. IRA prisoners also adopted hunger striking as a form of protest. Initially they were force-fed as well. In 1981, eight IRA prisoners in the Maze prison in Northern Ireland starved themselves to death. In the intervening years food refusal has occurred in prison, either to attract attention to a particular cause, such as the animal rights movement, or to protest about a personal situation, such as imminent removal from the country, length of sentence, innocence of the crime, or remorse for a serious offence, such as rape or murder. In immigration removal centres, food refusal is often a protest against detention, the handling of the person's immigration case, or the threat of removal/repatriation.

2.2 Legal precedents

Prior to 1995, *Leigh v Gladstone* (1909) and *R v Morton Brown, ex parte Ainsworth* (1909) provided the only case law on food refusal. The former stated that the Home Office had a duty to preserve the health of prisoners, even to the extent of forcibly feeding them. This legal decision was made in a climate of dramatic political conflict between the suffragist movement and the Government. It was also made at a time when suicide was a criminal act, as was the aiding and abetting of suicide. Prison doctors were therefore obliged to force-feed patients who were refusing food. The Suicide Act 1961 abolished the crime of suicide but retained the offence of aiding, abetting, counselling or procuring suicide. The death by self-starvation of one IRA prisoner in 1970, and the force-feeding of others, led in 1974 to a statement in the House of Commons by the then Home Secretary, Roy Jenkins, which indicated that as a matter of practice a prison doctor is not required to feed a prisoner artificially against their will.

In 1995 the judgment of the High Court case of *The Secretary of State for the Home Office v Robb* [1995] 2 WLR 722 provided clarification on forcible feeding and other non-consensual treatment of adults of sound mind in prison. In recent years the

courts have held that any adult of the requisite mental capacity has the right, save in certain limited circumstances, to refuse medical treatment. A patient who is entitled to treatment which might or would have the effect of prolonging their life but who refuses to consent to it, and because of that refusal subsequently dies, does not commit suicide. A doctor, who in accordance with his duty complies with the patient's wishes in such circumstances, does not aid and abet suicide.

There remained an undefined gap between the requirements of the prison doctor not to force-feed the patient and the legal imperative not to treat them against their will. There was also continued uncertainty as to the doctor's duty of care in a situation of advanced food refusal in which the patient might no longer possess the capacity for rational judgement. The 1995 judgment mentioned above resulted in advice to prison doctors and healthcare staff entitled *Food Refusal, Advance Directives and Mental Capacity*, which was issued as a Prison Service Dear Doctor Letter (DDL 96 (1) 1996). When the responsibility for commissioning healthcare services in prison transferred to the NHS, further advice was provided by the Department of Health in *Seeking Consent: Working with People in Prison*.

Guidance, which was previously prison specific, is now within the remit of the Mental Capacity Act 2005. The Act states that a person must be assumed to have capacity unless it is established that they lack capacity and must not be considered unable to make a decision merely because they make an unwise decision.

2.3 Consent to treatment, ethical and legal issues

Prisoners and detainees have the legal right to refuse food and fluid, as does anyone receiving treatment in the community. Although all efforts should be made to persuade individuals to eat and drink, feeding against the will of anyone who is competent to make their own decisions can be considered assault. Relevant issues are laid out in Sections 24 to 26 of the Mental Capacity Act 2005, which cover advance decisions to refuse any type of treatment; these decisions, and their legal effect, have been analysed in a number of judicial reviews. The Mental Capacity Act 2005 Code of Practice should be read alongside this document.

Refusal to consent to treatment, including food or fluid, remains binding and effective even where an individual subsequently becomes mentally or physically incompetent. This has been confirmed by the High Court in a case of a competent adult's anticipatory refusal of blood transfusion (in *HE v NHS Trust A and AE* [2003] EWHC 1017 (Fam)).

Artificial feeding, for example via a tube or vein, should not therefore be instigated in an individual who has previously refused nourishment, even if their physical condition has deteriorated to the point that they are no longer able to physically resist or continue to express their refusal.

The key characteristics of an advance decision for the purposes of the Mental Capacity Act 2005 are set out clearly in Appendix 2. They include the following:

- The decision must be made by a person who is 18 or over and at a time when the person has capacity to make it.
- A qualifying advance decision must specify the treatment that is being refused, although this can be in lay terms (for example using the term “tummy” instead of “stomach”). In order for this to apply to life-sustaining treatment, this must be specifically stated in the advance decision. For example, the person making the advance decision must state that it applies to refeeding as part of life-sustaining treatment, even if their life is at risk and without such treatment the person knows they will die.
- The decision and the statement verifying this must be in writing, signed and the signature witnessed. It is important to note that a person does not physically need to write their advance decision themselves. Advance decisions recorded in medical notes are considered to be in writing.
- If the person making the advance decision cannot sign it then another person can sign it for them at their direction and in their presence. As with a signature by the person themselves, the witness must be present when the third party signs.
- A person can change or completely withdraw the advance decision if they have capacity to do so.
- The withdrawal of an advance decision refusing life-sustaining treatment, such as food and fluid refusal, must be in writing.
- If there is doubt or a dispute about the existence, validity or applicability of an advance decision, then the Court of Protection can determine the issue.
- To be endorsable for the purpose of refusing life-supporting treatment, an advance decision should be valid, specific and applicable.

Useful documents to read in conjunction with these guidelines are the *Mental Capacity Act 2005 Code of Practice*, which outlines the legal framework and defines capacity, advance decisions and the role of the Independent Mental Capacity Advocate (IMCA)

service, and also *Making decisions: Helping people who have difficulty deciding for themselves: A guide for healthcare professionals*; both were published by the Department for Constitutional Affairs.

It is important to note that feeding against an individual's will can be undertaken in cases of severe anorexia nervosa since this is considered in law to render that individual incompetent of making an informed decision. The same principle may apply in certain other psychiatric conditions and it is therefore essential to consider psychological illness, or for that matter physical problems that could limit food intake, in any prisoner or detainee refusing food (see Section 4.4 on differential diagnosis).

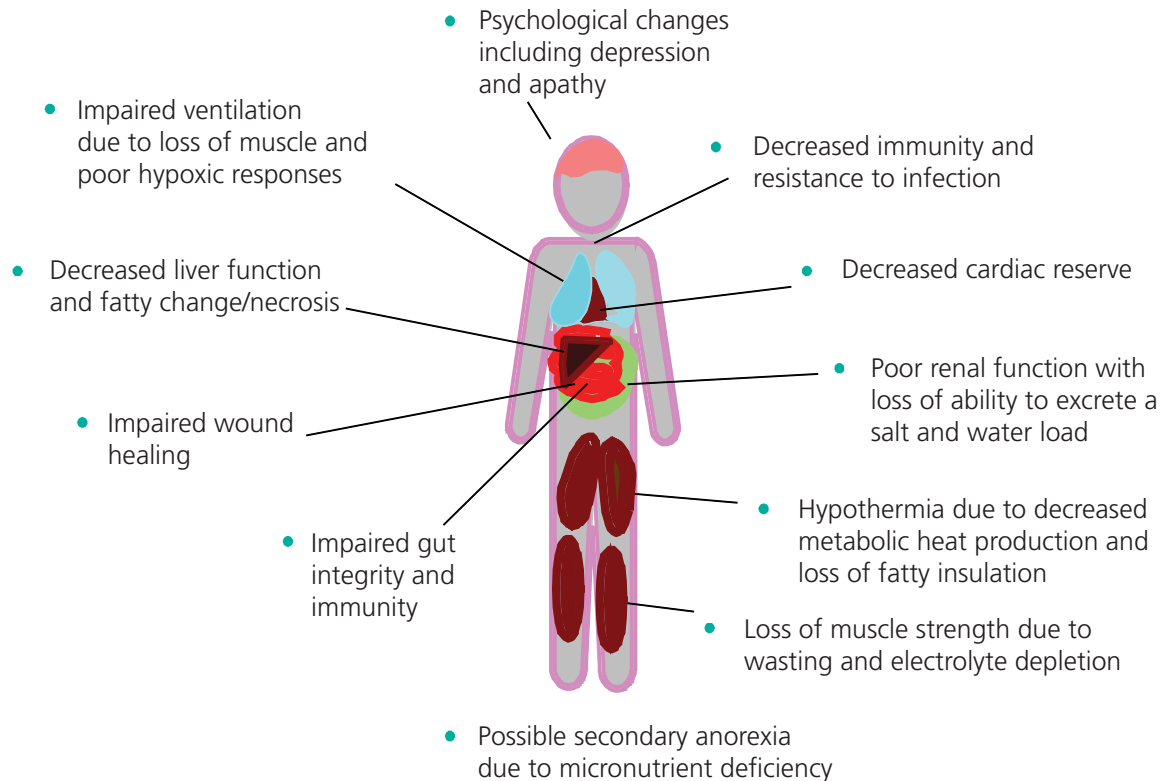
2.4 The effects of malnutrition

Malnutrition affects every system, causing vulnerability to infection, poor wound healing, impaired organ function, muscle weakness, depression and apathy. Some of these effects are shown in Figure 2.1.

Starvation is also accompanied by adaptive changes in metabolism, which, coupled with the poor nutritional intake, lead to changes in cell function and depletion of specific electrolytes, minerals and micronutrients. These need to be appreciated when offering care to the malnourished. The likely changes include:

- deficiencies of specific vitamins and trace elements;
- decreases in active cell membrane pumping in response to deficient energy, causing whole-body depletion of intracellular potassium, magnesium, and phosphate, with simultaneous increases in intracellular sodium and water;
- low insulin concentrations and a partial switch from carbohydrate metabolism to ketone metabolism to provide energy; and
- reductions in protein synthesis.

Figure 2.1: The effects of malnutrition



If an individual is well nourished at the beginning of a fast and is prepared to take adequate fluid, they are usually at little risk of dying from malnutrition for at least six to eight weeks after commencing a complete fast. Nevertheless, the onset of some debilitation and vulnerability is extremely rapid and declines in muscle strength and resistance to infection, for example, are measurable within three days of refusing all food. Many prisoners or detainees may be undernourished to some extent before commencing food refusal and, furthermore, intercurrent illness or other comorbidity has dramatic effects on starvation and chances of survival. Indeed, it is estimated that previously normally nourished individuals can die from malnutrition within three weeks of stopping food intake if they are severely ill.

It is vital to recognise that death from malnutrition is usually due to intercurrent infection or organ failure rather than from tissue loss per se. This reflects both specific nutrient deficiencies and the shutdown of metabolic functions which can occur when individuals are still of normal or even excessive weight, if they were obese at the start of their fast.

If an individual is refusing all fluids as well as food, deterioration is very rapid, with death quite possible within 7 to 14 days, especially during hotter periods of the year.

2.5 The principles of refeeding

As noted above, starvation is accompanied by depletion of whole-body electrolytes, minerals, vitamins and trace elements, along with a propensity to develop sodium and water overload. Giving too much food or fluid to malnourished individuals can therefore be dangerous because of demands for metabolic co-factors that cannot be met, along with risks from rapid movement of some micronutrients and electrolytes into cells, with simultaneous flux of sodium and water out of cells. There are two well-recognised forms of these “refeeding” problems: the classical “refeeding syndrome” and the “Wernicke-Korsakoff syndrome”.

2.5.1 Refeeding syndrome

Refeeding syndrome encompasses a range of life-threatening clinical and biochemical abnormalities occurring when food is given to starving individuals. Problems include:

- cardiac failure, pulmonary oedema and dysrhythmias;
- acute circulatory fluid overload or circulatory fluid depletion;
- hypophosphataemia;
- hypokalaemia;
- hypomagnesaemia and occasionally hypocalcaemia;
- hypoglycaemia;
- rhabdomyolysis;
- neurological manifestations; and
- liver dysfunction.

2.5.2 Wernicke-Korsakoff syndrome

This syndrome occurs due to acute thiamine deficiency because of increased thiamine demand as starving cells switch back to carbohydrate metabolism. Wernicke-Korsakoff syndrome is seen particularly frequently in alcoholics who may have low liver stores of thiamine, but it can occur in any starved individual on recommencement of food intake. This syndrome, accompanied by acute neurological abnormalities, involves one or more of the following:

- apathy and disorientation;
- nystagmus, ophthalmoplegia or other eye movement disorders;

- ataxia; and
- severe impairment of short-term memory often with confabulation.

In view of these refeeding risks, the initial aim of re-instigating nutrition is, in most cases, the prevention of any further decline in nutritional status and the gentle, controlled reversal of both the down-regulation of metabolism and any deficits in specific nutrients, minerals and electrolytes. However, when an individual has had little or no food intake for prolonged periods, initiation of feeding must sometimes be even more cautious, with early provision of energy and protein at levels that do not even meet their metabolic needs, while simultaneously providing generous quantities of all minerals and vitamins. Care to avoid salt and water overload is essential in every case and close biochemical monitoring is required in the more severely malnourished (see Section 7.2).

Prison healthcare or immigration removal centre staff should ensure that any blood samples are delivered to a hospital laboratory as soon as possible, and that, where clinically indicated, the laboratory is informed that an urgent result is required and whom to contact with the result. Healthcare staff should ensure that the result is chased up if it is not received within the time requested by the doctor in the prison or removal centre.

3 Presentation

3.1 Identification of a person who is refusing food

Since food refusal within prison or removal centres is usually a form of protest or entered into in order to raise the profile of an individual situation, early identification is extremely helpful. This allows maximum time to work with the individual, identify and if possible alleviate, the precipitating factor(s), and arrange counselling, psychological assessment, and assessment of mental capacity. Early recognition by staff should be encouraged by making them aware of the precipitating factors for food refusal. Both the UK Border Agency (UKBA) and National Offender Management Service (NOMS) take such situations very seriously and wish to manage them effectively, by assisting the individual to achieve a satisfactory solution to their dilemma.

3.2 Early recognition by staff

Early recognition can be facilitated by staff monitoring attendance at mealtimes and noting whether individuals return meals uneaten; additionally, individuals may discuss the situation with custodial staff or healthcare professionals. A system should be in place that highlights non-attendance for meals. It may be necessary for healthcare staff to review current medication when an individual stops eating (see Section 5).

3.3 Personal declaration

An individual may inform any member of staff that they plan to go on a fast. The staff member should assure them that such matters are taken very seriously, make enquiries about the issues that are motivating them to take such action, and discuss possible actions that will address the underlying issues, including consideration of opening an ACDT or ACCT if it is decided that this is appropriate. The opening of an ACCT/ACDT would be based on the assessment of the circumstances and motivations surrounding the refusal and on the medical and personal details more generally.

While it may become necessary for a prisoner or detainee to be asked if they wish to make an advance decision to refuse treatment, including artificial feeding, it is important that the timing of any discussion is considered carefully. If such discussions occur too early, it may lead the individual to feel that staff are pushing them into a corner. It is likely that such discussions will only become necessary when the individual is starting to become weak, and once efforts to de-escalate the situation have been made.

For prisons, food refusal is a reportable incident under Prison Service Order 1400. In summary, this requires governors to:

- consider preparing written contingency plans to assist in the management of food refusal;
- report all food refusal incidents that are considered life threatening to Intelligence and Operations (IOU); and
- enter all reportable incidents onto the local Incident Reporting System-National Offender Management Information System (IRS/C-NOMIS) database within 72 hours (24 hours if telephone reportable).

4 Early assessment

4.1 Establish the primary reason for food refusal

In immigration and removal centres the primary reason for food refusal is likely to be a protest at ongoing detention or removal from the country, but there may be other issues involved – even a perceived undue delay in repatriation. Prisoners may opt to refuse food and/or fluids as a method of protesting their innocence, highlighting a cause or remorse for an offence, such as a murder.

It is important that any lack of mental capacity and/or mental illness is identified. Clearly established mental illnesses, particularly those in which delusional thought is common, such as depression or psychosis, may influence behaviour. Individuals may believe that their food is poisoned or their bowels will block if food is eaten. The lack of mental capacity must be considered, as its lack may influence matters by making the subject unable to comprehend the seriousness of the situation and the consequence that food refusal can have a fatal outcome. As a consequence, it is advisable to arrange a mental health and mental capacity assessment within the first seven to ten days, and at least before the person becomes too weak for thorough assessment. Obviously such an assessment may require translation services if English is not spoken to a sufficiently high standard.

4.2 Clinical assessment

It is important to explain to the individual that they are being examined so that healthcare professionals can monitor their health and well-being as it is the staff's objective to keep them as well as possible during the period of time they are fasting.

As long as the individual refusing food agrees to the process, it is essential to make a full initial medical assessment. This includes a brief history of past and present medical problems and a full clinical examination. Specific note should be made of body weight, temperature, pulse, blood pressure and respiration rates as a baseline, so that future observations can be made against this baseline. Undernourished individuals may not show the normal signs of infection and, paradoxically, undernourishment may cause a fall in body temperature and white cell count rather than the normally observed rise. A minimum screen of chest X-ray, urine microbiology and blood cultures must accompany any suspicion of intercurrent illness or non-specific deterioration in the severely malnourished, with other tests as appropriate.

A thorough assessment of nutritional status is always needed. This consists of establishing levels of recent food intake and usual body weight (from previously recorded measures and/or an individual's recollection), and performing a specific nutritional examination. This comprises measurement of current body weight and height to calculate body mass index (BMI) (namely weight in kilograms divided by height in metres squared, i.e. $BMI = \text{kg/m}^2$) and inspection for the presence of muscle wasting and loss of subcutaneous fat. Clothed appearances can be very deceptive especially in individuals who have developed limb oedema, which can make extremely thin arms and legs look quite robust. Individuals must therefore be examined in suitable clinical surroundings, dressed in only underwear. If this is not possible, you must at least ensure that you pull up their sleeve to get a more accurate picture of true upper-arm circumference.

Specific checks for signs of vitamin and other nutrient deficiencies must also be made. These include:

- *Mouth*: A red, sore tongue suggests B group vitamin deficiencies, while a smooth tongue may reflect iron deficiency. If the individual is consuming any food or fluid, ask if it is painful to eat or drink and whether their sense of taste is normal (some deficiencies, such as zinc, can cause loss or alteration of taste sensation). Poor iron status can also cause sores at each side of the mouth which hurt when eating or speaking (angular cheilitis), while more generalised peri-oral sores, especially if the patient also has a perineal rash, suggest zinc depletion. Swollen, bleeding gums with loss of teeth occur in scurvy from vitamin C deficiency.
- *Hair*: Recent abnormal hair loss or a change in hair growth towards finer, curly hair can follow any severe or chronic illness but is particularly seen in malnourished individuals developing trace element deficiencies.
- *Skin*: Specifically look for thinning of the skin, damage from minimal trauma and poor repair to such damage. The skin over the knuckles and back of the hand seems particularly vulnerable and appearances may resemble severe dermatitis. The skin over the anterior aspect of the lower leg also seems particularly prone to changes from malnourishment, with dry, fragile, flaking "snake" skin suggestive of essential fatty acid deficiency. Specific rashes or skin abnormalities can also indicate deficiencies such as zinc, vitamin C and some B group vitamins.
- *Nails*: Periods of poor nutrition lead to poor nail growth and nails that break easily. If these periods have been intermittent, the nails are sometimes horizontally ridged. Fragile, thin, spoon-shaped nails are another sign of iron deficiency.

While performing the general clinical examination, pay close attention to hydration status, noting signs of both under- and over-hydration. Dehydration is suggested by loss of skin turgor, pale and cold extremities, a dry tongue, dry oral mucosa and sunken eyes. Fluid overload is suggested by a raised jugular venous pressure or signs of pulmonary congestion. The development of oedema in malnourished individuals who have no other likely cause, such as congestive cardiac failure, is a worrying sign, often occurring in individuals who are developing infection or significant organ dysfunction. In the past, it has often been ascribed to a low serum albumin caused by malnourishment, but in recent years this view has changed and most experts now agree that albumin levels have nothing to do with nutritional status. Even patients approaching death from malnutrition, for example with a BMI of 10–11, often have entirely normal albumin levels, and even low protein starvation does not cause low albumin per se although it makes it more likely that the individual will become ill while still at a higher body weight. Low albumin with or without oedema should therefore be viewed as a marker of illness, indicating that the individual is mounting an inflammatory response, usually to overt or hidden infection.

Medical assessments and advice from health professionals working for the prison or immigration removal centre may be perceived as threats and, if this is the case, the possibility of finding alternative “impartial” health professionals to undertake such assessments should be explored.

4.3 Laboratory assessments

Although haematological and biochemical measurements can contribute to nutritional assessment, none are specific for nutritional risk. If the prisoner or detainee is agreeable, the following parameters should be checked initially, with plans to monitor them as food refusal continues, and especially to continue their monitoring were the individual to decide to recommence feeding.

Full blood count (FBC): Malnutrition may be accompanied by anaemia and, when present, haematinics should be measured. Many undernourished individuals have a low white cell count with possible reductions in both lymphocytes and neutrophils. A raised neutrophil count should raise the suspicion of infection but so should a sudden fall. The severely malnourished can have partial bone marrow failure which is unmasked if white cells accumulate in an area of infection but cannot be replaced rapidly enough in the circulation.

Urea and electrolytes: Malnourished individuals often have a dangerously low plasma potassium level, particularly with any refeeding. However, because it is a predominantly intracellular cation, even significant whole-body depletion may not be accompanied by low plasma values. Indeed, high plasma potassium levels may be

seen in an individual who is actually depleted in whole-body terms, if they have also developed any renal impairment from ingesting little or no fluid. Obviously, the biochemical abnormalities may then include raised or rising creatinine and urea levels, but in individuals of very low body weight, these renal indices may be far lower than expected for a given level of renal dysfunction.

Magnesium and calcium: Low magnesium levels are also common in malnourishment, especially with refeeding. Low calcium levels are less common and, if present, should prompt assessment of vitamin D status since they suggest osteomalacia (bone alkaline phosphatase levels may be raised in these circumstances).

Phosphate: Low plasma phosphate levels are extremely common in the malnourished and pose significant dangers. However, as with potassium, it is important to recognise that whole-body depletion may not be reflected in low plasma values and, indeed, that plasma levels may be high if there is any degree of renal failure. If this is the case, phosphate levels may plummet to a life-threatening degree with refeeding, especially if simultaneous fluid administration corrects any renal impairment.

C-reactive protein (CRP) and erythrocyte sedimentation rate (ESR): An unexplained raised or rising CRP or ESR should be taken to indicate infection, even if there are no other symptoms or signs, and in the severely malnourished this should prompt treatment (see below).

Glucose: Glucose levels are often low and may require specific support in the very malnourished. An acute hypoglycaemic episode is another indicator of latent infection.

Liver function tests: Liver function tests are frequently abnormal in the malnourished, usually with raised transaminases (alanine transaminase (ALT) or aspartate transaminase (AST)) with lesser effects on alkaline phosphatase (ALP). Synthetic function reflected in albumin or International Normalised Ratio, prothrombin time (INR) is usually normal, and any disturbance of these should be considered worrying. Low albumin is seen with infection (usually accompanied by raised CRP) while increased INR usually reflects acute liver steatosis and necrosis, often as the result of refeeding. In these circumstances, transaminase levels can be very high, reaching values in the thousands.

If the individual does develop abnormal blood tests, the implications should be discussed with them and decisions made on what, if any, treatments are acceptable to them.

4.4 Assessment of capacity

A person's capacity refers specifically to their capacity to make a particular decision at the time it needs to be made. To help someone make a decision for him or herself, the following need to be considered:

- Use simple language, through an interpreter if required.
- Explain any risks.
- Does the person have the relevant information? In the case of food refusal, the person needs to understand that continuing to refuse food will eventually be fatal.
- However, the individual does have choices. Have alternatives been suggested and discussed?
- Are there any interventions that might prevent them taking this step?
- Describe the foreseeable consequences of making the decision to refuse food and later to refuse all life-giving support, and ensure that the information is clearly understood.
- The person must be able to hold the information in their mind for long enough to use it to make an effective decision.
- Check the individual's understanding after a few minutes.
- Be aware of cultural, ethical and religious factors that shape the person's way of thinking, behaving and communicating.

4.4.1 Capacity

- The starting assumption must always be that a person has capacity to make a decision, unless it can be established that they lack capacity.
- Does the person have an impairment of mind or brain, or is there some disturbance affecting the way their mind or brain works?

4.4.2 Communication

- Does the person fully understand the situation?
- Could information be provided in a simpler manner?
- Do they need help with communication (for example, from an interpreter, advocate or friend)?

4.4.3 Make the person feel at ease

- Do not rush the decision.
- Ensure that the person understands that the staff will always act in their best interest.

4.4.4 Support the person

- Can anyone else help them to make the decision?
- Who should make the decision about capacity? It is ultimately up to the healthcare professional responsible for the patient's treatment to ensure that capacity is assessed.

People involved in assessing information will need to share that information. While there are professional codes of confidentiality, as a general rule professionals must ask the individual if the information can be shared with others in the multidisciplinary team caring for them.

4.5 Differential diagnosis

4.5.1 Psychiatric illness

Any possibility of mental illness, especially depression, psychosis or anorexia nervosa, must be considered in every case of food refusal. Clearly, particular care is needed whenever there is a language barrier and if there is any suspicion of mental illness, experienced psychiatric assessment, with access to translators if necessary, will be required. Food refusal may occur in severe depression, in association with a psychosis or in a toxic confusional state. If the clinician has any concerns about the possibility of existing mental illness, a referral to a psychiatrist for mental health assessment must occur.

4.5.2 Physical illness

Many factors/conditions may precipitate anorexia and weight loss, including TB, cancer, and gastroenterological disease such as Crohn's disease and severe infection. Once again, poor communication by the individual may reduce the clinician's suspicion and make diagnosis difficult.

4.6 Information for the individual on the consequences of starvation

Individuals who are refusing food or fluid should be told of the consequences of their actions and provided with information on how their body may respond and how they may feel. An example of such information is available in Appendix 1. In addition, it may be helpful to provide the individual with the patient information booklet *Making decisions about your health, welfare and finances... Who decides when you can't?*, which is published in 11 languages and is available on the Ministry of Justice website (www.justice.gov.uk) (see Appendix 1). It is important that an individual is fully aware of the consequences of their decision making. The patient does have choices and will be supported by healthcare professionals in their choices. The healthcare professionals will continue in active dialogue with the individual throughout their time in custody.

5 Initial strategies to alleviate food refusal

It may be possible to encourage the individual to take some food, or at least milk. This strategy may be more successful if the prisoner or detainee is being reassured that their concerns are being addressed. Withdrawal of all medication on the grounds of the person not eating is likely to be counterproductive, but some medications may only be safely given if the person is eating.

5.1 Initial case review

Soon after an individual is identified, or identifies him- or herself, as voluntarily refusing food a case review should be held. Prisons or immigration and removal centres may care to utilise the case review mechanism set out in Prison Service Order 2700. In removal centres, the immigration manager is most likely to chair the conference, while in a prison establishment the chair would be expected to be the relevant appropriate manager; other participants should include healthcare staff, residential staff and those most likely to bring about the resolution of the situation, such as religious representatives, Embassy staff, translators, and other advocates from the community and those suggested by the individual.

The aim is to identify how best to resolve the situation by developing strategies for psychological, physical and social well-being. It is also important to identify how the individual wishes to be managed clinically if the situation cannot be resolved satisfactorily.

5.2 Recording an advance decision

An advance decision enables someone aged 18 and over, while still capable, to refuse specified medical treatment in the future, when they may lack capacity to consent to or refuse that treatment.

The Mental Capacity Act 2005 imposes particular legal recruitments and safeguards on making an advance decision to refuse life-sustaining treatment, which must be met in order for the decision to be valid and binding.

- It must be in writing.
- If the person is unable to write, someone else should write their advance decision down for them. For example, a family member can write down the decision on their behalf, or a healthcare professional can record it in the person's healthcare notes.

- The person must sign the advance decision. If they are unable to sign, they can direct someone to sign on their behalf in their presence.
- The person making the decision must sign in the presence of a witness to their signature. The witness must then sign the document in the presence of the person making the advance decision. If the person making the advance decision is unable to sign, the witness can witness them directing someone else to sign on their behalf. The witness must then sign to indicate that they have witnessed the nominated person signing the document in front of the person making the advance decision.
- The advance decision must include a clear, specific written statement from the person making the advance decision that the advance decision is to apply to the specific treatment even if life is at risk.
- Section 4(10) of the Mental Capacity Act 2005 states that life-sustaining treatment is treatment that a healthcare professional who is providing care to the person regards as necessary to sustain life. The decision will not just depend on the type of treatment. It will also depend on the circumstances in which the healthcare professional is giving it. For example, in some situations, antibiotics may be life sustaining but in others they can be used to treat conditions that do not threaten life.
- Artificial nutrition and hydration (ANH) is a recognised form of medical treatment. ANH involves using tubes to provide nutrition and fluids to someone who cannot take them by mouth. It bypasses the natural mechanisms that control hunger and thirst and requires clinical monitoring. An advance decision can refuse ANH. Refusing ANH in an advance decision is likely to result in the person's death, if the advance decision is followed.
- It is very important for a person making an advance decision to refuse life-sustaining treatment to discuss it with a healthcare professional. Nevertheless, it is not compulsory. A healthcare professional will be able to explain:
 - what type of treatment may be life sustaining and in what circumstances; and
 - the implications and consequences of refusing such treatment.
- An advance decision cannot refuse actions that are needed to keep a person comfortable (sometimes called basic or essential care). Examples include providing warmth or shelter, actions to keep a person clean and the offer of food and water by mouth. Section 5 of the Act allows healthcare professionals to carry out these actions in the best interest of a person who lacks capacity to consent (see Chapter 6). An advance decision can refuse ANH.

5.2.1 The role of the witness

Witnessing a person's signature is essential, where the person is making an advance decision to refuse life-sustaining treatment. The role of the witness is to witness the person's signature and confirm the wishes set out in the advance decision. It may be helpful to give a description of the relationship between the witness and the person making the advance decision. The witness is not certifying that the person has the capacity to make the advance decision – even if the witness is a healthcare professional or knows the person.

If a healthcare professional is acting as a witness and has also assessed the person's capacity, then he or she should make a record of the assessment, because acting as a witness does not prove that there has been an assessment.

- Healthcare professionals will be protected from liability if they stop or withhold treatment if they reasonably believe that an advance decision that is valid and applicable exists.
- At the time treatment is required, the healthcare professional must try to find out if the individual has withdrawn the decision to refuse life-sustaining treatment; such withdrawal must be in writing.
- If a healthcare professional disagrees with the advance decision, they must transfer the individual's care to another professional.

It is good practice to record this information.

5.3 Recording advance decisions in custodial settings

In the community it is acceptable to record the outcome of discussions in the medical records. However, advice from the Ministry of Justice Legal Directorate is that it is preferable to have an advance decision recorded in a separate document used solely for that purpose. It is sensible to have at least one witness for such discussions, and preferably two. The discussion should ascertain that the individual understands the situation and the consequences of their actions. This document should record that their judgement is not impaired either through lack of mental capacity, mental illness, or through the presence of a physical disorder such as an organic confusional state.

6 Ongoing care and management

6.1 Regular reviews

Healthcare professionals must remain in active dialogue with the individual throughout their time in custody. In addition, they should undertake regular reassessments of a starving individual's physical and mental state should be undertaken within limits dictated by the individual's compliance. However, since there is no hard evidence of the levels of clinical monitoring needed, the recommendations below should be viewed as general guidance with firm decisions on the frequency and nature of regular reviews requiring judgements dependent upon the individual's response to starvation, the experience of other professionals involved in their medical care, and the care setting.

Reassessments of individuals refusing food but taking fluids should generally be on a weekly basis at first, as long as they were of normal nutritional status at the outset. It is good practice to undertake regular case reviews; Prison Service Order 2700 provides useful guidelines on case reviews. More frequent clinical assessments will be needed if they were malnourished at the outset and once the individual shows signs of overt debilitation or any intercurrent illness. Eventually, daily assessment will be required, and daily evaluation will be needed from the outset in individuals refusing all fluids as well as food. If the individual has an open ACDT or ACCT plan, regular assessments will be part of the plan.

Evaluations should include a brief physical and psychological assessment with specific discussion on each occasion regarding the individual's current wishes on feeding and their wishes in relation to actions to be taken if they were to fall ill and become unable to express their opinion.

If the individual agrees, blood tests to monitor infection and nutritional status should be performed at approximately weekly intervals, increasing to twice weekly if abnormalities develop. They may even be needed daily if abnormalities are life threatening and the individual is prepared to receive specific treatment, such as potassium and/or phosphate supplements.

If at any time the individual decides to amend his or her advance decision, this should be recorded in the same manner as the advance decision itself and witnessed by at least one other individual in line with good practice (Appendix 2).

6.2 Supplements and food choices

Individuals who are refusing all food should be encouraged to drink adequately but discouraged from consuming excessive volumes of fluid to try to offset their hunger. They should be invited to take a balanced multivitamin and trace element supplement daily, explaining that this should help to maintain their general well-being and even their comfort in terms of sore mouth, skin breakdown etc. If they agree to take small quantities of food or nutritious drinks, items or selections containing a mixture of all types of nutrients should be advised.

6.3 Additional confidential support

Additional support may be helpful in facilitating good communication between the prisoner or detainee and those caring for them, and other prison or immigration removal centre staff. A relative or friend might provide suitable support but, where no suitable person can be identified, support could be obtained from a number of groups including the chaplaincy or a prison visitors group. In immigration and removal centres independent doctors may also provide such support (see Appendix 3).

6.4 Independent Mental Capacity Advocate service

The new Independent Mental Capacity Advocate (IMCA) service created by the Mental Capacity Act 2005 provides safeguards for people when they lack capacity at the time they need to make a decision, particularly if they:

- are facing a decision about serious medical treatment (defined as treatment that involves stopping treatment or withholding treatment where there is a fine balance between the likely benefits and the risks, or where a decision between a choice of treatments is finely balanced, or where what is proposed has serious consequences); and
- have nobody else who is willing and able to represent them or be consulted in the process of working out their best interests.

IMCAs must act within the principles and requirements of the Mental Capacity Act 2005. Health and social care decision makers have a duty to instruct IMCAs to support a person who lacks capacity and represent their views to a decision maker. Because their role is to support and represent the person who lacks capacity, they have the right to access relevant health and social care records.

The IMCA:

- is independent of the person making the decision;
- provides support for the person who lacks capacity;
- represents the person without capacity in discussions to work out whether the proposed decision is in the person's best interests;
- provides information to help others work out what is in the person's best interests; and
- raises questions or challenges decisions which appear not to be in the best interests of the person.

The information the IMCA provides must be taken into account by decision makers whenever they are determining what is in a person's best interests. But IMCAs have a different role from many other advocates, particularly in that they provide statutory advocacy, have a right to meet in private the person they are supporting, and are allowed access to relevant healthcare records and social care records. The roles and responsibilities of IMCAs and the bodies who instruct them are set out in the Code of Practice for the Mental Capacity Act 2005.

The Code specifically covers the use of IMCAs in prison if the circumstances meet the relevant conditions, including if decisions are being made about serious medical treatment for people who lack capacity in respect of that time of decision making. Further information can be found in the leaflet *Making Decisions: The Independent Mental Capacity Advocate (IMCA) Service* (www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_073932).

6.5 Independent doctors as advocates

It is not unusual for people refusing food to identify prison or removal centre clinicians as agents of those with whom the food refuser is in dispute. As a result, they may withhold consent for monitoring and investigations that are in their best interests. Under these circumstances, a doctor independent of the prison or immigration removal centre may be able to explain to the person refusing food that cooperation with monitoring, investigations or treatment is in their interests. Therefore, a visit from such an independent doctor can be helpful to both the healthcare team and their patient, and good communication between the professionals involved is important. An alternative approach is transfer to an NHS hospital, which is discussed in the following section.

6.6 Transfer to hospital

It should be normal practice for the prisoner or detainee refusing food or fluids to be assessed in a local hospital once the person has become weak, dehydrated or probably dehydrated, oedematous, or has developed significant biochemical abnormalities. This takes them out of the situation in which their protest has the greatest relevance, and brings them into contact with healthcare professionals who have no link with their detention or case. Under these circumstances, it may be hoped that they will reconsider their situation and allow rehydration and refeeding to commence. If treatment is refused, the hospital may decide to discharge back to the removal centre or prison.

7 Reintroduction of food and fluids

An individual who decides to recommence eating after refusing food for more than a few days is at potential risk of refeeding problems, especially if they had been malnourished before commencing food refusal. Once again, it must be emphasised that no hard evidence exists to guide practice, but refeeding syndrome can be fatal and hence caution is needed.

The degree of risk should be assessed in every case, with guidance on reintroducing food dependent on the risk category that is ascribed to the individual. In extreme cases, this may entail tightly controlled reintroduction of any nutrients with careful physical and biochemical monitoring in a hospital setting.

Individuals at modest, high or extreme risk from refeeding syndrome should have their management discussed with a clinical nutritional specialist or hospital physician at the end of a fast. Hospital admission may well be the most reliable way to institute refeeding for these individuals so that their clinical state, including temperature, blood pressure, respiration rate, body weight, fluid balance and biochemistry, can be rigorously monitored while controlled dietary intake and adequate vitamin and electrolyte supplements are started.

7.1 Risk of refeeding syndrome

7.1.1 Negligible risk of refeeding syndrome

Individuals who have fasted for less than five days, with BMIs $>18.5\text{kg/m}^2$, are at little or no risk of refeeding problems, although they will need careful assessment of hydration status and possibly tests of renal function if they have refused fluid for several days.

7.1.2 Modest risk of refeeding syndrome

Individuals will be at some risk of problems on refeeding if they fulfil any one of the following criteria:

- a BMI $<18.5\text{kg/m}^2$;
- loss of $>10\%$ of their body weight since starting their period of food refusal;
- little or no food intake for between five and ten days.

7.1.3 High risk of refeeding syndrome

Individuals are at high risk of problems on refeeding if they fulfil either one of the following major risk factors, or two or more of the following lesser risk factors:

Major risk factors

- a BMI $<16\text{kg/m}^2$;
- unintentional weight loss $>15\%$ of body weight since starting food refusal;
- little or no nutritional intake for more than ten days;
- low potassium, magnesium or phosphate levels before the onset of refeeding.

Lesser risk factors

- a BMI $<18.5\text{kg/m}^2$;
- weight loss $>10\%$;
- little or no nutritional intake for more than five days;
- a history of alcohol abuse or use of some drugs including insulin, chemotherapy, antacids or diuretics.

In all “at risk” cases, the blood tests for biochemical or haematological abnormalities should be taken before commencement of refeeding and abnormalities likely to reflect starvation changes should prompt reconsideration of risk category, which may increase. The presence of any significant comorbidity or intercurrent infection also leads to greater risks and should also prompt re-categorisation.

7.1.4 Extreme risk of refeeding syndrome

Individuals at the highest risk of life-threatening problems include those with *more* than one of the following major risk factors:

- a BMI $<16\text{kg/m}^2$;
- unintentional weight loss $>15\%$ of body weight since starting food refusal;
- little or no nutritional intake for more than ten days;
- low potassium, magnesium or phosphate levels before the onset of refeeding;

- a history of alcohol abuse or use of some drugs including insulin, chemotherapy, antacids or diuretics;
- significant comorbidity or intercurrent infection, either evident on clinical assessment or suggested by the development of either high or low white cell counts, rising c-reactive protein (CRP) or falling albumin, or high or low blood glucose levels.

7.2 Management of risk

7.2.1 Management of negligible risk of refeeding syndrome

Individuals in this category may be allowed to eat and drink freely, and no monitoring is necessary.

7.2.2 Management of modest risk of refeeding syndrome

Individuals at modest risk of refeeding syndrome should be advised to eat only limited amounts of varied foods (total of <30kcal/kg/day) for the first two days, with provision of a balanced daily multivitamin and trace element supplement. The food may be of any type, dependent upon cultural background. Large quantities of food should not be consumed at this stage, but it is important that the balanced supplements are provided in case they are lacking something. Fluid provision should generally be limited to around 30ml/kg/day, although this figure could be doubled during reversal of clear dehydration assessed either clinically or on urea/creatinine results. Blood tests should be repeated at approximately 24 and 48 hours of refeeding, with advice changing to that suggested for higher risk individuals as appropriate. If no problems arise over the first 48 hours of refeeding, levels can be increased, building up to unrestricted ingestion by five days. The balanced micronutrient supplement should be continued until body weight has recovered to pre-fasting values.

7.2.3 Management of high risk of refeeding syndrome

Individuals remaining in the high-risk category for refeeding syndrome after their blood test results are known should be advised to limit intake to 20kcal/kg/day for the first 48 hours, taking either small quantities of different food types (i.e. different items in keeping with their cultural background that are likely to provide a balance of protein, carbohydrate and fat) or oral sip feeds in small amounts spread throughout the 24 hours. If no problems occur, intake can be increased by increments of 10kcal/kg/day. All restrictions on food intake can be lifted after day five if no problems have arisen and the individual is consuming a total of 50kcal/kg/day. Fluid provision should generally be limited to around 30ml/kg/day, although this figure could be doubled during reversal of clear dehydration assessed either clinically or on urea/creatinine results. These individuals should be managed in an in-patient facility with on-site 24-hour nurse cover. Their care

should be discussed with the local hospital physicians, and hospital admission for the initial period should be seriously considered in that discussion, the details of which must be recorded whenever it is agreed that admission does not need to take place.

All individuals at high risk while refeeding should also receive:

- oral supplements of potassium, phosphate and magnesium unless their prefeeding blood tests are abnormally high. Likely requirements are:
 - potassium (2–4 mmol/kg/day);
 - phosphate (0.3–0.6mmol/kg/day);
 - magnesium (0.2mmol/kg/day intravenously, or 0.4mmol/kg/day orally);
and
- vitamin and micronutrient supplements including:
 - oral thiamine (100mg twice daily for ten days);
 - vitamin B Co Strong (one twice a day);
 - a daily balanced multivitamin and trace element supplement.

During the first week, daily monitoring of sodium, potassium, phosphate, magnesium, calcium and glucose levels should occur. Liver function tests should be monitored at least twice weekly.

Refeeding should take place in a clinical setting with careful observation for any signs of fluid overload, infection or general deterioration, and there should be a low threshold for transferring the individual to hospital should any clinical or biochemical abnormalities become concerning. Likely causes of such concern would include: potassium levels $<3.0\text{mmol/l}$; magnesium levels $<0.5\text{mmol/l}$; phosphate levels $<0.5\text{mmol/l}$; ALT or AST >4 x upper limit of normal range and rising; or persistent glucose level <2 .

7.2.4 Management of extreme risk of refeeding syndrome

Individuals at the highest risk of life-threatening refeeding problems should be admitted to hospital and treated according to the NICE guidelines on refeeding (specifically the NICE guidelines on nutrition support in adults, 2006). Clinical management will include:

- restoration and monitoring of circulatory volume, fluid balance and electrolytes;
- the use of balanced constant levels of feeding via nasogastric tube or two to four hourly increments of complete liquid oral supplements to provide a total

of 10kcal/kg/day for the first 48 hours (5kcal/kg/day in extreme cases, e.g. BMI <12); most feeds contain 1kcal/ml, so daily volumes are likely to be in the 300–600 ml range); then, assuming stable clinical and biochemical status, increased amounts in order to meet estimated needs over the subsequent four to seven days;

- anticipation of the need for electrolyte and mineral supplements likely to amount to:
 - potassium (2–4 mmol/kg/day);
 - phosphate (0.3–0.6 mmol/kg/day);
 - magnesium (0.2 mmol/kg/day intravenously, or 0.4mmol/kg/day orally);

provision will need to be reviewed on a daily basis with close laboratory monitoring;

- provision of vitamin supplements including:
 - thiamine (usually Pabrinex I + II daily I.V. for three days followed by oral thiamine at 100mg twice daily for up to seven days);
 - vitamin B Co Strong 1 twice daily;
 - a daily balanced multivitamin and trace element supplement;
- ECG monitoring should occur for at least the first 48 hours of feeding – looking for evidence of electrolyte disturbance, potassium, calcium and magnesium;
- daily monitoring during the first week of sodium, potassium, phosphate, magnesium, calcium and glucose levels should occur; liver tests should be performed twice a week.

Feeding should not be withheld in individuals with low levels of potassium, magnesium or phosphate since electrolyte deficits are predominantly intracellular and hence cannot be corrected without commencing low levels of simultaneous feeding. Furthermore, the presence of normal or high-serum electrolytes does not exclude the risk of refeeding syndrome as these individuals may have whole-body electrolyte depletion, which may amount to thousands of millimoles. Individuals with renal failure and raised serum electrolytes are therefore likely to require supplementation as refeeding and fluid replacement progresses and renal function improves.

8 Terminal care

Those undergoing a fast should have their clinical state and treatment wishes constantly under review, especially in the event of a sudden deterioration in their well-being. While clinical staff have no desire to contravene a patient's wishes, they also do not want the patient to put themselves in extreme danger, if there is any doubt that this would now be contrary to the patient's wishes. The individual would then be required to sign to confirm that they have withdrawn their advance decision. If the individual is deteriorating, and is still resolute that they don't wish to be treated, it may be helpful to discuss with the patient and hospital specialist staff the possibility of a reassessment in hospital. The possibility here is that transfer to hospital and care by another clinical team may provide the opportunity, which is face-saving for some, for the individual to reconsider the situation and break their fast. Having spent time in hospital, and if unwilling to break their fast, it is reasonable for them to return to the immigration removal centre or prison.

At this stage there will need to be close liaison with UKBA or NOMS and the individual's family. The appropriate minister(s) will need to be briefed. If the individual is in a prison this will be the responsibility of the Safer Custody and Operational Policy Group, NOMS. If the individual is in an immigration removal centre this will be the responsibility of UKBA. The prisoner or detainee will be best managed in a healthcare bed, in a healthcare centre with 24-hour nursing cover.

8.1 Physical care

In this situation a high degree of nursing care will be required. Medication may be given with the individual's consent to ease any pain and/or discomfort they may experience as this is not precluded by an advance decision refusing life support. Expertise from both healthcare and community-based specialists in palliative care, such as community nursing services, should be sought. This can provide invaluable guidance on possible adaptations to the individual's care, such as additional nursing care, changes to their medication, or the suitability of pressure-relieving beds.

8.2 Psychological support

Psychological support and, where appropriate, support for religion or faith according to the person's beliefs should be provided by centre or prison staff, in conjunction with any advocate the individual chooses, and any outside expertise deemed necessary. Should the prisoner or detainee decide to end their food or fluid refusal, or wish to be treated during this phase, then transfer to hospital should take place promptly.

Appendix 1: Refusing food or drink – prisoner or detainee advice sheet

Introduction

You have decided to refuse or severely limit your intake of food and/or drink. This decision is your right but it is important that you know about the likely effects of your actions at the outset. This advice sheet will help you to understand the effects of starvation and why you will be given different medical advice at different stages if you continue to refuse to eat or drink. It also explains why you might need to take great care and even have close medical supervision if you decide to start eating and drinking again after a prolonged period of starvation.

Your legal rights

Anybody has the legal right to refuse food and fluids and, although we will try to persuade you to eat and drink, we will not try to feed you against your will unless independent experts believe that you have a psychological or physical illness that makes you unable to decide for yourself. The relevant parts of UK law that allow you to make your own decisions about taking food and fluids (or any other type of treatment) are laid out in Sections 24 to 26 of the Mental Capacity Act 2005 and you can see the details of this if you wish and in the patient information booklet *Making decisions about your health, welfare and finances... Who decides when you can't?* which is published in 11 languages and is available on the Ministry of Justice website (www.justice.gov.uk).

Your refusal to consent to having food or fluids remains binding on everybody even if starvation or illness makes you unable to go on resisting feeding or other treatment. You will not therefore be given food or fluids artificially if you continue to make it clear that this is your wish, even if you can no longer express your desires by either talking or indicating them. This applies even if it means that you will die. However, you can change your mind at any time to stop your fast and agree to appropriate treatment.

The effects of starvation

Starvation affects every part of your body and it will make you weak and vulnerable to infections. Your skin may become fragile and you are likely to develop uncomfortable or painful sores, particularly in the mouth and on bony pressure points. You may feel very cold and people often become constipated although some

develop diarrhoea. Lack of food is likely to affect your thinking, probably making you very depressed or withdrawn. Eventually, it will start to damage your major organs which can fail completely, leading to death.

If you are well nourished when you begin to refuse food, and you are prepared to take adequate fluids, you are unlikely to die from starvation for at least six to eight weeks, even if you eat nothing. However, you will be affected in some ways very quickly. Weakness and lowered resistance to infection can occur within three days of refusing all food and, if you are already undernourished when you stop eating, or you have any illness, survival will be much shorter. Even well-nourished individuals can die from starvation in three weeks if they become ill.

The effects of avoiding fluids

If you decide to refuse all fluids, your deterioration in health will be extremely rapid and you could die within a week to 10 days, especially during hot weather.

Medical care during food refusal

If you have decided to refuse food or fluids, you will be offered medical care. This will include an initial assessment of your general health and eating habits and a general physical examination. We would also recommend that you have some blood tests to be sure that you are starting in good health or, that if you do have a problem, you are fully aware of it and the extra risks it might entail. We will also recommend that you take at least one multivitamin supplement each day and that any food that you do decide to eat is reasonably balanced from a nutritional point of view.

If you go on fasting, we will offer you a further medical assessment each week, and more frequent assessments as you become weaker and more likely to develop problems. We will also suggest weekly blood tests which might also need to become more frequent. Whenever you have a medical assessment (and quite possibly at other times), you will be asked to confirm that you do wish to go on refusing food and/or fluids and that you understand the increasing risks.

The dangers while refeeding

When the body starves, it loses many minerals and vitamins and the function of all cells and organs is decreased. This can make reintroduction of food quite dangerous. As a result, if you do decide at some point to stop your food refusal protest, you may be advised very strongly to eat very little at first while taking plenty of vitamin and mineral supplement tablets. Indeed, if you have become very malnourished, the dangers of refeeding can be so extreme that you might even be advised to go to

hospital for very close monitoring of your heart and blood chemistry while food is trickled back into your system, possibly via a tube in the nose.

Choosing a representative

Since refusing food will eventually lead to your becoming very ill and even dying, you will be asked to find a suitable person to ensure that your wishes are followed once you cannot express them yourself. This could be a relative or friend who you trust, but could also be a member of your own faith, your doctor, an independent doctor if in an immigration removal centre, or another health professional of your choice. Information on the protocol for visits by external medical practitioners to detainees in immigration removal centres can be provided for you. It is clearly essential that you discuss all of your wishes with your representative throughout your period of food refusal and that you feel that they can represent your intentions accurately. You should also appreciate that this may be very difficult for a relative or friend.

Appendix 2: Mental Capacity Act 2005 explanatory notes amended for the management of people refusing food in immigration removal centres and prisons

The Mental Capacity Act 2005 received Royal Assent on 7 April 2005. It aims to clarify a number of legal uncertainties and to reform and update the current law where decisions need to be made on behalf of others. The Act governs decision making on behalf of adults; it covers a wide range of decisions on personal welfare as well as financial matters and substitute decision making, such as made by clinicians involved in the management of people refusing food.

Key principles of the Act

The starting point is a presumption of capacity. A person must be assumed to have capacity until it is proved otherwise.

Mental capacity

For a patient to have the requisite mental capacity to refuse medical treatment (including refusal of food and/or fluids), a doctor must be satisfied that the patient is able to:

- i) comprehend and retain information about the treatment offered;
- ii) believe that information; and
- iii) weigh up the information, balancing risks against needs.

As a matter of practice in custodial settings or places of detention, such a test should be applied through consultation between healthcare staff and, if necessary, a psychiatrist.

A person must also be supported to make his or her own decision, as far as it is practicable to do so. The Act requires “all practicable steps” to be taken to help the person. This could include, for example, making sure that the person is in an environment in which he or she is comfortable, or involving an expert in helping the

person express their views. It is expressly provided that a person is not to be treated as lacking capacity to make a decision simply because he makes an unwise decision. This means that a person who has the necessary ability to make the decision has the right to make irrational or eccentric decisions that others may not judge to be in his best interests.

Advance decisions to refuse treatment

Some people already choose to make such decisions and their legal effect has been analysed in a number of judicial decisions. It has been confirmed by the High Court that a competent adult patient's anticipatory refusal of consent remains binding and effective notwithstanding that he has subsequently become incompetent. Broadly, this clarifies the current common law rules, integrating them into the broader scheme of the Act. An "advance decision" is a special type of advance statement which represents an actual decision to refuse treatment, albeit at an earlier date.

The key characteristics of an advance decision for the purposes of the Act are as follows:

- The decision must be valid, specific and applicable.
- It must be made by a person who is 18 or over and at a time when the person has capacity to make it. A qualifying advance decision must specify the treatment that is being refused, although this can be in lay terms (for example, using "tummy" instead of "stomach").
- It may specify particular circumstances, again in lay terms, in which the refusal will apply. A person can change or completely withdraw the advance decision if he has capacity to do so. The withdrawal, including a partial withdrawal, of an advance decision does not need to be in writing and can be by any means, preferably witnessed.
- An advance decision will not be applicable if the person actually has capacity to make the decision when the treatment concerned is proposed.
- It will also not be applicable to treatments or in circumstances not specified in the decision.
- The decision will not be applicable if there are reasonable grounds for believing that the current circumstances were not anticipated by the person and, if they had been anticipated by him, would have affected his decision. For example, there may be new medications available that radically change the outlook for a particular condition and make treatment much less burdensome than was previously the case.

- An advance decision will not apply to life-sustaining treatment unless a statement is made confirming that the decision applies to that life-sustaining treatment, even if life is at risk. The decision and the statement verifying it must be in writing, signed and the signature witnessed. It is important to note that a person does not physically need to write his advance decision himself. Advance decisions recorded in medical notes are considered to be in writing.
- If the maker of the advance decision cannot sign then another person can sign for him at his direction and in his presence. As with a signature by the person himself, the witness must be present when the third party signs.
- A treatment provider may safely treat unless satisfied that there is a valid and applicable qualifying advance refusal; and a treatment provider may safely withhold or withdraw treatment as long as he has reasonable grounds for believing that there is a valid and applicable qualifying advance decision.
- If there is doubt or a dispute about the existence, validity or applicability of an advance decision, then the Court of Protection can determine the issue.

Appendix 3: Protocol for visits by external medical practitioners to detainees in immigration removal centres

1. The purposes of visits by external medical practitioners to detainees in immigration removal centres in accordance with Detention Centre Rule 33(7) are:
 - i) to provide a second medical opinion of the patient's medical needs and the current medical treatment; and/or
 - ii) to prepare medical reports for the patient's legal advisers.

Whilst the second opinion may be shared with the healthcare staff at centres, the responsibility for the ongoing treatment of the patient remains with the centre healthcare staff.

2. A visiting medical practitioner must provide written evidence that he/she is registered with the General Medical Council and/or the General Dental Council.
3. Detainees must confirm in writing to the healthcare centre that they wish to be visited by the named external medical practitioner and that they consent to the medical practitioner having access to his/her medical notes. Removal centres must advise detainees of their rights to, and methods for, requesting such a visit.
4. The named external medical practitioner will contact the healthcare centre at the removal centre to make an appointment to visit the detainee and to provide written confirmation that he/she satisfies the requirements in paragraph 2 above. This information will not be retained by the removal centre once verified. The healthcare centre will contact the centre manager to ensure that the criteria are met and that the visit is approved.
5. Healthcare centres will endeavour to meet the visit time requested by the external medical practitioner, or offer alternative appointment times if the requested time is not possible. The visit will be held in a healthcare room with appropriate examination facilities including an examination couch, hand-washing facilities and a door that affords full privacy.
6. If a healthcare room is not available at the time of the requested visit, a standard visit in the centre legal visits room will be offered as an alternative.

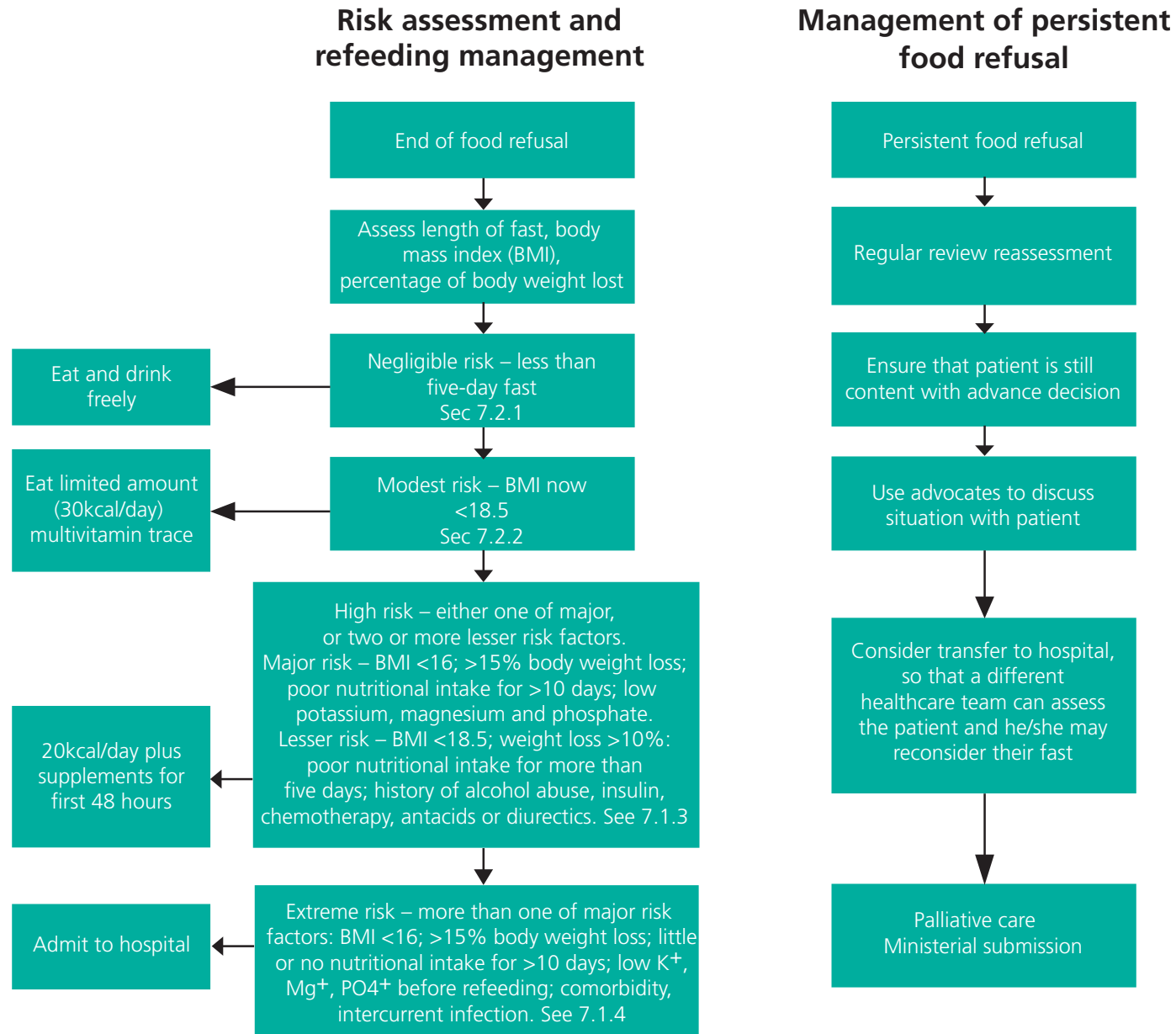
7. The healthcare centre will provide the external medical practitioner with full access to the detainee's comprehensive medical notes, nursing notes and details of his/her medical treatment.
8. Where good medical practice dictates, and with the patient's consent, the external medical practitioner will either make a direct entry into the patient's medical notes or provide the healthcare centre with written notes of his/her assessment, by email, fax or post in order to provide continuity of care for the patient. Similarly, if there are acute medical concerns about the patient, they should be conveyed without delay, either by telephone or by direct contact with healthcare staff in the centre.
9. Both the external medical practitioner and the healthcare centre staff will adhere to normal standards of professional conduct and to the guidelines set out in the General Medical Council's *Good Medical Practice*, the Department of Health's *Independent Health Care: National minimum standards, regulations* and the *Private and Voluntary Health Care Regulations 2001* and, in the case of other healthcare professionals, the guidance of their relevant professional bodies.

Brian Pollett, Director, Detention Services
Borders and Immigration Authority
8 December 2006

Appendix 4: Initial assessment of individual refusing food



Appendix 5: Clinical assessment of risk of refeeding syndrome and management of refeeding following a period of fasting



Appendix 6: References

1. National Institute for Health and Clinical Excellence (2006) *Clinical guideline – Nutrition support in adults: Oral nutrition support, enteral tube feeding and parenteral nutrition*, London: NICE.
2. Department of Health (2002) *Seeking Consent: Working with People in Prison*, London: DH.
3. Department for Constitutional Affairs (2007) *Mental Capacity Act 2005 Code of Practice*, London: DCA.
4. Mental Capacity Act information leaflets and information booklets, including:
Booklet 1: For people who may be unable to make some decisions for themselves who wish to plan ahead for the future; and
Booklet 3: For people who work in health and social care
Available at: www.dca.gov.uk/legal-policy/mental-capacity/publications.htm.
5. Department of Health (2008) *The first annual report of the Independent Mental Capacity Advocacy Service, Year 1, April 2007–March 2008*, London: DH.



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