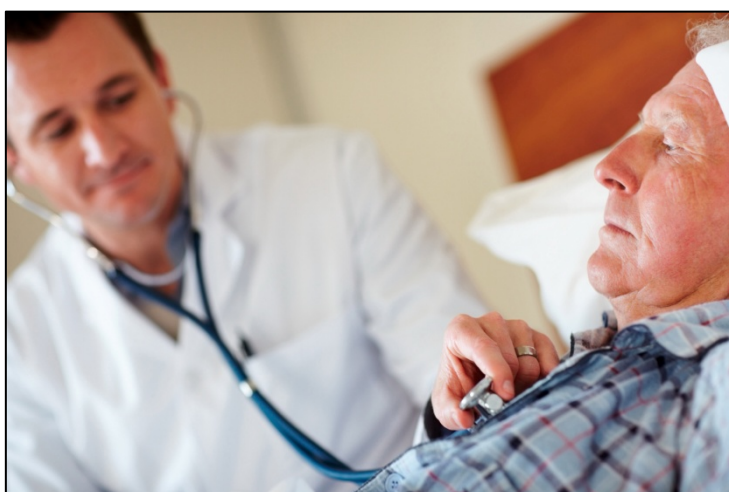


Serious Medical Treatment Decisions

# BEST PRACTICE GUIDANCE FOR IMCA<sub>s</sub>

## PEG FEEDS



## Contents

<b>Introduction</b> .....	<b>3</b>
Definition of SMT .....	3
Serious consequences.....	3
Decision maker .....	4
History .....	4
<b>What is a PEG?</b> .....	<b>5</b>
Why is it prescribed?.....	5
Who is it prescribed for? .....	6
Different types of artificial nutrition hydration (ANH) .....	6
<b>PEG feeds and dementia</b> .....	<b>6</b>
<b>Medical Side Effects and Risks and Burdens</b> .....	<b>8</b>
Minor complications.....	8
Major complications .....	8
Benefits.....	9
<b>Ethics</b> .....	<b>9</b>
<b>Cultural and religious factors</b> .....	<b>10</b>
<b>Questions to ask the Decision Maker</b> .....	<b>11</b>
<b>Questions to ask the person and those that know the person</b> .....	<b>11</b>
What does food represent to the person? .....	11
Will having a PEG fitted impact on the relationship the person has with carers? .....	11
Did the person indicate their views on being fed by a PEG? .....	12
Will social activities such as going out be affected or interrupted? .....	12
<b>Points to highlight within a report:</b> .....	<b>12</b>
<b>Further guidance &amp; resources</b> .....	<b>13</b>
<b>Best practice guidance range</b> .....	<b>14</b>

## Introduction

This guidance was developed by the Action for Advocacy IMCA Support Project and is part of the Serious Medical Treatment (SMT) best practice guidance. It is aimed at IMCAs who are supporting and representing people when best interests decisions about serious medical treatment are being made. Much of the IMCA's role is to ensure that what is important to the person is considered when the decision is being made, to ensure relevant questions are asked on behalf of the person and alternatives suggested where it is believed they would be better suited to the person's wishes and feelings. The guidance aims to support the IMCA's work.

This guidance will cover SMT decisions about percutaneous endoscopic gastrostomy tubes commonly referred to as a PEG feeding tube, where the person lacks capacity to give or withhold consent to the treatment. It should be read in conjunction with Action for Advocacy's Instruction and Report Writing guidance where further information about IMCA instruction or writing IMCA reports is needed<sup>1</sup>.

## Definition of SMT

Regulations for England and Wales define serious medical treatment<sup>2</sup>. It involves:

- giving new treatment
- stopping treatment that has already started, or
- withholding treatment that could be offered

In circumstances where:

- if a single treatment is proposed there is a fine balance between the likely benefits and the burdens to the patient
- a decision between choice of treatments is finely balanced, or
- what is proposed is likely to have serious consequences for the patient

## Serious consequences

Serious consequences are those that could have a *serious impact* on the patient either from the treatment itself or due to wider implications such as:

- prolonged pain
- distress

---

<sup>1</sup> [www.actionforadvocacy.org.uk](http://www.actionforadvocacy.org.uk)

<sup>2</sup> <http://www.legislation.gov.uk/ukxi/2006/1832/regulation/4/made>

- side effects of the treatment such as reduced immunity
- major consequences such as stopping life sustaining treatment or amputation
- serious impact on a patient's future life choices

A person will have a right to an IMCA if such treatment is being considered on their behalf.

### Decision maker

The decision maker is the person within the responsible body who is required to ultimately make the decision. For decisions about serious medical treatment the responsible body is the relevant NHS organisation. The MCA Code of Practice (6.17)<sup>3</sup> clarifies this further by advising whomever is providing treatment will be the decision maker therefore for different decisions this can be a range of professionals, but for most SMT decisions this is likely to be a medical consultant with specific expertise in the area of decision making e.g. orthopedics, dentistry, oncology, surgery etc.

### History

The PEG feed was first performed in 1979 at the Rainbow Babies and Children's Hospital in Cleveland, Ohio by Dr. Jeffrey Ponsky and Dr. Michael Gauderer<sup>4</sup> pediatric surgeons, on a 4 month old baby and originally intended for use on children who had neurological problems that affected their ability to swallow. The PEG provided the necessary nourishment they needed. It soon went on to be used in adults as well. Controversy has however surrounded PEG feeds due to the ethical issues, in terms of keeping someone artificially alive, in particular where they don't have the capacity to consent to this and their wishes are not known. Legal disputes have occurred in both the USA where Terri Schiavo's husband (a woman left in a permanent vegetative state after collapsing and suffering irreparable brain damage) fought in the courts for his wife's feeding tube to be removed and the UK, which saw the case of Lesley Burke who fought for the right to live through artificial nutrition in the event he loses the capacity to communicate. It continues to be performed on a wide range of people that have the capacity to understand and consent to the treatment as well as those who don't.

<sup>3</sup> <http://www.publicguardian.gov.uk/docs/mca-code-practice-0509.pdf>

<sup>4</sup> <http://www.therubins.com/geninfo/feedtubes.htm>

## What is a PEG?

The PEG is a feeding tube that goes directly into the stomach therefore bypassing both the mouth and throat and is recommended for some people that have difficulties in eating or swallowing. The person is then fed this way and a dietician assists in terms of nutrition, which includes the frequency and amount of feed into the tube. An endoscopy (the procedure of where an endoscope, a tube that has a light and a camera on one end is fed into the person's mouth, down the food pipe and then into the stomach) is carried out and a small cut is made in the abdomen for the tube to come out, this is then attached to the feeding bag which contains the liquid nutrition. The insertion of a PEG feeding tube is usually treated as a day case, some patients require anesthetic in order to for the endoscopy to be performed particularly where they may become overly anxious or for those patients where capacity is an issue and they would be unable to follow instruction or relax enough to have the endoscope inserted.

A speech and language therapist carries out an assessment in order to determine the necessity as well as risks and/or benefits for the person. A dietician will be involved to ensure the person is prescribed the right amount of nutrition and can then support the person themselves to administer their own feed or their carers where they are unable to.

## Why is it prescribed?

PEGs are given to people of all ages including children where they are experiencing issues with eating such as being unable to eat at all due to a serious physical illness or not eating enough due to their condition. Others may be unable to swallow or experience difficulties with swallowing (dysphagia) and aspirate. When a person aspirates this means that food or drink is inhaled so instead of going down their oesophagus and into their stomach, some matter may end up on their trachea or lungs. The lungs are normally able to break down foreign matter, however where this is a continued problem and there is a build up of enough foreign matter on the lungs this can lead to infections or damage to the lungs, that in itself can lead to other serious or ongoing health problems such as bronchopneumonia (a bacterial form of pneumonia), chest infections, bronchiectasis (a form of lung disease) or asthma. A fatal consequence of a build up on the lungs is that the patient could simply drown. A PEG feed is an artificial method of providing nutrition, some people

will still be able to eat but will be fitted with a PEG for increased nutrition, for others a PEG will replace the oral intake of food completely.

### Who is it prescribed for?

The range of patients that will be fitted with a PEG varies widely. Some neurological conditions such as motor neurone disease can affect a person's ability to chew or swallow due to the muscles involved in this becoming weak or slow. Some people with multiple sclerosis may experience dysphagia as a symptom of their illness or those with cystic fibrosis may require a PEG to ensure nutritionally they are kept well when they are experiencing difficulties in eating due to symptoms of their condition or due to secondary illnesses. Others that may be affected by chewing or swallowing difficulties are people who have had stroke, a head injury or surgery to the head/neck, some people with dementia may also lose the ability to chew food properly or swallow, for others with dementia they may become depressed or experience side effects from medication which can impact on their desire/ability to eat.

### Different types of artificial nutrition hydration (ANH)

There are a range of feeding tube procedures given for different reasons and needs of the patient such as:

**Nasogastric tubes** – is usually used for those that need feeding via a tube for short amount of time.

**Radiologically inserted gastrostomy tube (RIG).** These tubes are put directly into the stomach and prescribed usually for those that are unable to have an endoscopy.

**Percutaneous endoscopic jejunostomy tubes (JEJ or PEJ tubes).** These are inserted through an endoscopy and are usually performed on those that have stomach or throat surgery.

Standard PEG feeds are nut, gluten and lactose free; soya feeds are also available for vegans.

### PEG feeds and dementia

Many studies have questioned the use of PEG feeds on those with dementia (older people and those with dementia are one of the largest client groups to receive or

need a PEG). Some studies have also highlighted a high death rate soon after the procedure is carried out.

In the British Geriatrics Society *Good Practice Guide of Guidelines, Policy Statements and Statements of Good Practice - Nutritional Advice in Common Clinical Situations*<sup>5</sup> this research is summarised including the factors that contribute to PEG feeds for patients with dementia:

*“Anorexia, weight loss and also dysphagia are common in patients with advanced dementia. In these patients intercurrent infection, environmental change, depression, poor carer rapport, pain, oral hygiene, ill-fitting dentures and nursing availability are just some potentially reversible and treatable causes of reduced food and fluid intake”*

*“The best available evidence, in the absence of randomised controlled trials, suggests that PEG tube feeding does not improve overall prognosis in patients with advanced dementia<sup>6</sup>. It does not prevent aspiration<sup>7</sup>, prolong survival, improve quality of life, functional status or nutritional status<sup>8,9</sup>. PEG tubes are generally poorly tolerated by patients with dementia and there is some evidence that hand feeding can be as effective<sup>10</sup>.”*

The GMC Guidance: *Treatment and care towards the end of life: good practice in decision-making*<sup>11</sup> advises:

*If a patient is in the end stage of a disease or condition, but you judge that their death*

<sup>5</sup> [http://www.bgs.org.uk/Publications/Compendium/compend\\_4-8.htm](http://www.bgs.org.uk/Publications/Compendium/compend_4-8.htm)

<sup>6</sup> Gillick M. (2000) Rethinking the role of tube feeding in patients with advanced dementia. N Eng J Med 342, 206-210

<sup>7</sup> Finucane T., Christmas C, Travis K (1999) Tube feeding inpatients with advanced dementia: a review of the evidence. JAMA 282, 1365 - 70

<sup>8</sup> Finucane T. Bynum J. (1996) Use of tube feeding to prevent aspiration pneumonia. Lancet 348, 1421-1424

<sup>9</sup> Mitchell S., Berkowitz R., Lawson F., Lipsitz L. (2000) a cross-national survey of tube feeding decisions in cognitively impaired older persons. J Am Geriatr Soc 48, 391-39

<sup>10</sup> Mitchell S., Buchanan J., Littlehale S., Hamel M. (2004) Tube-feeding versus hand-feeding nursing home residents with advanced dementia: a cost comparison. JAMDA 5(2) S23 – 29.

<sup>11</sup> [http://www.gmc-uk.org/static/documents/content/End\\_of\\_life.pdf](http://www.gmc-uk.org/static/documents/content/End_of_life.pdf)

*is not expected within hours or days, you must provide clinically assisted nutrition or hydration if it would be of overall benefit to them, taking into account the patient's beliefs and values, any previous request for nutrition or hydration by tube or drip and any other views they previously expressed about their care. The patient's request must be given weight and, when the benefits, burdens and risks are finely balanced, will usually be the deciding factor.*

Where there is a view that artificial nutrition and hydration would not benefit the patient: *In these circumstances you must make sure that the patient's interests have been thoroughly considered. This means you must take all reasonable steps to get a second opinion from a senior clinician (who might be from another discipline) who has experience of the patient's condition but who is not already directly involved in the patient's care*

So whilst any research carried out with regards to PEG feeds needs to be strongly considered, this in itself does not determine the outcome. The best interests checklist, principles of the Act including the views of others as well as any advanced decisions made must still be taken into account.

## Medical Side Effects and Risks and Burdens

Complications can occur with any medical procedure and it is important to have some understanding of what the risks may be although it should be noted that these risks are a general overview and may increase or decrease depending on the individual's history, current presentation or assessment.

### Minor complications

- PEGS can become clogged.
- They can also be accidentally or deliberately removed and for some patients this may mean the use of restraints.
- There is a risk of infection around the site area so this needs to be kept clean.

### Major complications

- Chest infections or aspiration pneumonia
- Allergic reactions
- Bleeding
- Perforation to the stomach or oesophagus
- Death



The above risks are relatively rare but need to be considered.

### Benefits

Nutritionally the person will receive what they need and medication can also be administered via the PEG, for patients who have had an acute stroke, studies have shown that those fitted with a PEG in the early stages after an acute stroke, recovery is increased in comparison to those that didn't receive a PEG (this can be linked to the fact that many people who have a stroke were malnourished prior to the stroke and so the insertion of PEG nutritionally benefits someone)<sup>12</sup>.

However the question that needs to be asked for the person that is being considered for a PEG is whether this will benefit them – in the broadest context. Consideration will need to be given to whether it will prolong their life and enhance their own quality of life (from their perspective) or will it prolong their death? What will the impact be on their physical, emotional and mental health? The benefit of the PEG feed must be individual to that person in the same context that risks, side effects or burdens are.

### Ethics

Amongst the medical community, a common concern is providing a PEG feeding tube for someone who is in the terminal stages of illness where it is believed that prescribing a PEG may be prolonging a person dying rather than their living. This element will be specific to the individual rather than the condition they have but will need to be considered by all those involved.

With respect to the role of an IMCA the challenge in this instance is not so much about a persons wishes about living but how they would wish to die. Some people will have made very clear advanced statements in their lives about where they would want to die (as well as how) when the time comes, others may not. Whilst the role of the IMCA is not about being able to make predictions as to what a person would want, consideration needs to be given to this issue when the IMCA is consulting with the person and others in their life.

---

<sup>12</sup> Clinical guideline 68 Stroke: diagnosis and initial management of acute stroke and transient ischaemic attack (TIA)

<http://www.nice.org.uk/nicemedia/pdf/CG68NICEGuideline.pdf>

Quality of life is an individual issue, what is quality for some, may not be acceptable for others. When quality of life is raised as a factor in decision-making, it is important to ensure that it is based on the knowledge of that individual whom the decision is about and what is known about what they perceived as quality of life and not what is perceived as quality of life for the medical professionals, family, carers or the advocate involved within the decision making.

### **Cultural and religious factors**

A patient's religious or cultural beliefs may impact on the decision and so it is important to determine as far as possible whether they practiced any particular faith as well as being able to ascertain cultural beliefs. All societies have different cultures and this is seen through traditions, beliefs, language, where a person has lived, their experiences, surroundings as well as interactions with others, these will all impact on the way we see and experience the world and ultimately what our own culture is.

It is not possible to find this much detail from a person when working as an IMCA due to both time constraints on the decision making process and the ability to form a long term advocate/client relationship as well as communication or comprehension factors. However IMCAs should consider the above when meeting with the client as well as speaking to others. Culture can sometimes narrowly viewed as only being connected to religion. Similarly, it is sometimes only taken into consideration when a person's culture is different to the prevailing culture of the society they currently live in but it is inherent in all of us and as such needs to be understood in order to be able to represent the person within this decision.

Many religions are explicit as to their views on how life should be preserved, when medical intervention should cease as well as when it is appropriate to continue. Again when working on a timely decision and with someone who may be unable to communicate effectively, being able to research differing religions and their belief system can prove difficult but it is important to ask whether it is known not only if a person was born into a faith (or converted to a faith) but whether they practiced this. It is important not to assume that merely belonging to a religious group means someone either agrees or practices this faith.

## Questions to ask the Decision Maker

Q: What risks and benefits will the person face from this procedure?

Q: Is supported hand feeding an option?

Q: Will the PEG impact on the person's current illness or physical condition?

Q: Will the person be able to continue to eat or drink at all?

Q: Is the procedure reversible?

Q: Will this procedure improve the chances of recovery or impact on recovery (for example if the person has had a stroke or they are in a coma, or brain damaged with no meaningful chance of recovery)?

Q: Will the procedure impact on other aspects of their life (for example will their care needs increase to the point their current accommodation is no longer suitable)?

Q: What maintenance is required and who will carry this out?

Q: Has the person indicated their preference, wishes, views or feelings either in the past or now (this includes verbal communication as well as non verbal communication or observations)

Q: Where it is assessed that the person is likely to die either with or without a PEG feed, how will having a PEG fitted impact on them (for example a patient may die more quickly without a PEG but be in a more painful state, their life may be prolonged with a PEG but known to be an unsatisfactory state).

## Questions to ask the person and those that know the person

### What does food represent to the person?

For some people food is merely viewed as fuel to keep the body going, for others it's a hugely important social aspect of their life for example having a routine of eating Sunday roast, a cooked breakfast, a meal in a restaurant once a week or the opportunity to go out and socialise, be part of the community or with family, an expression of cultural or religious traditions. Indeed it is not unheard of (particularly where PEG feeds are common treatments for certain physical conditions) for someone to make an advance declaration that they would rather not live longer if it means their main enjoyment socially is taken from them.

### Will having a PEG fitted impact on the relationship the person has with carers?

Some people that require PEG feeds will have been at a stage of needing someone to be with them at meal times whether it was to provide supervision from a health

and safety perspective or whether a carer was hand feeding. No longer having that time and attention from a carer may be perceived as more empowering for the person but alternatively this may have been their only opportunity for 1:1 interaction so consideration needs to be given to the impact of this on the person as well as what alternative interaction can replace feeding.

### **Did the person indicate their views on being fed by a PEG?**

Some people will clearly be able to communicate their wishes and whilst deemed to lack capacity, this does not mean they cannot express a view, others may have limited verbal communication and express their views through their behaviour. It is important to note though that, unless the person is surrounded by those that know them well, and can understand all their behaviour, that interpretation is not overly used.

### **Will social activities such as going out be affected or interrupted?**

Will having the PEG procedure now mean it is more difficult for a person to go out, for example if they need to have regular feeds and that are provided in a particular environment or by particular people (carers, dieticians). Aside from the physical activity possibly being affected, what will the impact be on the person's psychological state if they are now expected to be in the house for long periods of time.

### **Points to highlight within a report:**

- The physical impact on the person
- The person's usual diet or social habits for example if they go out for a meal once a week, will this be affected and if so, will this then impact on them emotionally or psychologically
- Expressed preferences of the person
- Views of their family or friends in terms of the actual procedure but also their perception of what decision the person would have made if they could
- The least restrictive option
- Relevant legal or medical guidance

## Further guidance & resources

### General Medical Council

[www.gmc-uk.org](http://www.gmc-uk.org)

### National Institute for Clinical Excellence

[www.nice.org.uk](http://www.nice.org.uk)

### British Geriatrics Society

[www.bgs.org.uk](http://www.bgs.org.uk)

## Best practice guidance range

The IMCA Support Project has produced a range of guidance on the involvement of IMCAs in SMT decisions that can be accessed on the Action for Advocacy website under IMCA Support Project, articles and resources.

### **The involvement of Independent Mental Capacity Advocates in Serious Medical Treatment Decisions**

Best Practice Guidance for Healthcare Professionals and IMCAs. Includes case examples, example policies and useful forms.

### **Serious Medical Treatment - Specific Decision Guidance for IMCAs**

The guides cover some common SMT decisions IMCAs may be involved in.

Do Not Attempt Resuscitation (DNAR)

PEG Feeds

Chemotherapy

End of Life Care

Dentistry

ECT Factsheet

### **Serious Medical Treatment Checklist (for the involvement of IMCAs)**

A useful A4 chart, which gives information, aimed at health professionals about when to instruct IMCA.

### **IMCA involvement in SMT decisions leaflet**

A leaflet aimed at healthcare professionals which gives information on the IMCA role and when and how to instruct IMCA.

[www.actionforadvocacy.org.uk](http://www.actionforadvocacy.org.uk)

## Action for Advocacy

Registered as a company in England and Wales No 4942158 Charity Number  
1103575 Registered Office:

The Oasis Centre  
75 Westminster Bridge Road  
London  
SE1 7HS

Tel: 0207 9214395  
Fax: 0207 9214201

[www.actionforadvocacy.org.uk](http://www.actionforadvocacy.org.uk)

The IMCA Support Project is funded by The Department of Health

© Action for Advocacy 2011

---