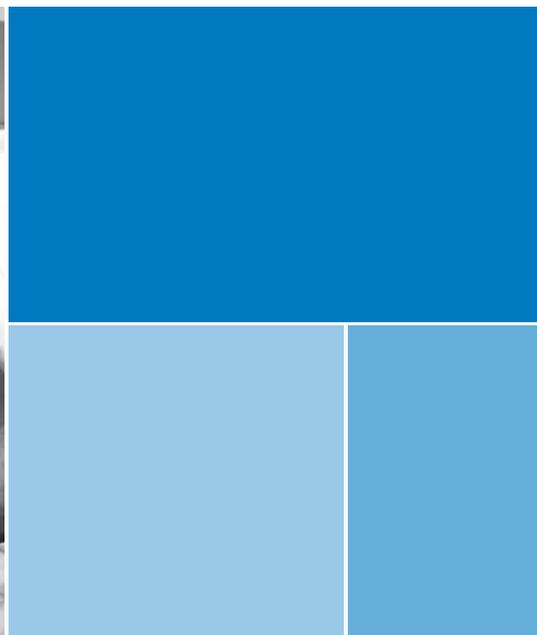


Advice for people with swallowing difficulties



Patient and Carer Information

Introduction

Some people can develop swallowing difficulties and managing these can be very challenging for everyone involved. A hospital admission to manage swallowing difficulties is unlikely to be of benefit to some people.

This guide provides practical guidance on helping people with swallowing difficulties to maintain their food, fluid and medication intake as well as is possible.

This guide considers swallowing difficulties occurring among:

- Elderly and frail patients admitted with an acute illness
- Patients with moderate to severe chronic cognitive impairment with or without an acute illness
- Patients with dementia
- Patients of any age receiving end of life care.

Causes of swallowing difficulties

There are lots of possible causes of swallowing difficulties and these can develop suddenly (acute) or more gradually (chronic).

Acute Causes

- Dental or infections within the mouth
- Infection e.g. urinary tract infection
- Loss of consciousness due to an acute illness
- Acute neurological event e.g. stroke
- Medication
- Possible effects from radiotherapy on head and neck.

Chronic Causes

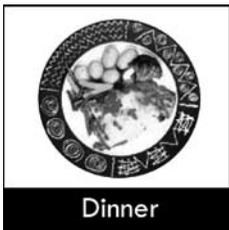
- Progression of dementia
- Swallowing difficulties following a stroke
- End of life (due to disease progression)
- Depression/anxiety (loss of appetite, food refusal or abnormal perception of food)
- Narrowing of the throat e.g. tumour
- Progressive neurological condition e.g. Parkinson's disease, Motor Neurone Disease, Multiple Sclerosis.

Depending on the cause of swallowing difficulty there are some questions which health care professionals will want to consider:

- Is the difficulty a sudden or gradual onset?
- What is the likely cause of the difficulty?
- Is the condition reversible by treatment?
- Would treatment be in the patient's best interests?

Any person who develops persistent swallowing difficulties should be referred to a **Speech and Language Therapist (SALT)** for a **swallowing assessment**. The patient may also benefit from referral to a Dietician for dietary advice and support.

Eating and dementia



Even in the early stage of the disease the symptoms of dementia can have a significant impact on food intake and the body's nutritional health.

In advanced dementia the impact of the disease on nutrition results in some people not being able to request food or drinks, inability to feed themselves, recognise food, refusing to eat and having significant swallowing difficulties. The swallowing difficulties may be referred to as an 'unsafe' swallow, but this does not necessarily mean that the person should stop eating.

In patients with advanced dementia who also have diabetes, it is important to ensure that they do not feel unwell because of the diabetes. However very tight control of diabetes at this time is not necessary and any changes to diabetic control should be achieved using medication if possible rather than by restricting food.

Swallowing

Advice from a Speech and Language Therapist (SALT) is valuable as they can advise on appropriate positioning to minimise the risk of choking (food or fluid 'going down the wrong way').

The following advice is likely to help when feeding people who have an unsafe swallow, but it is important to be aware that individual advice from a SALT is always valuable.

NB: People who have had a community assessment will not always require a further SALT assessment in hospital, unless their swallow has deteriorated.

Practical advice for swallowing

- Soft or pureed food and thickened fluids may be advised as these can be safer for people with swallowing difficulties to manage
- Extremes of food temperature (comfortably hot or very cold) stimulates swallowing more strongly than lukewarm food
- Try to make sure that food is strongly flavoured (e.g. very sweet, spicy, sharp etc.) as extremes of flavour stimulate swallowing more strongly than bland flavours
- Alternate temperature and taste within a meal. e.g. alternate spoonfuls of sweet and savoury foods or alternate spoonfuls of hot and very cold foods to stimulate stronger swallowing
- Offer an ice cold drink prior to a meal or in between mouthfuls to stimulate stronger swallowing

- Throughout the meal, snack or drink keep reminding the person about the food or drink and remind him/her to swallow each mouthful
- Make sure the person has swallowed before offering another mouthful
- Use gentle, physical prompts to encourage self-feeding e.g. put the utensil/cup in the person's hand and help guide it to his/her mouth
- Try to provide food and fluids when the person with dementia is most alert
- Encourage small amounts of the correct texture of food and fluids frequently throughout the day
- Try to keep the eating environment as calm and free from distractions as possible
- Try to maintain good mouth care (such as brushing teeth, rinsing mouth with mouthwash etc.). Reducing the amount of bacteria in the mouth may help to protect against chest infections.

An 'unsafe' swallow

If a person is diagnosed as having an unsafe swallow, health care professionals should not advise that the person is placed 'nil by mouth'.

There is no evidence of harm from continuing to offer small amounts of fluids and food at end of life, provided that the person is correctly positioned and sufficiently alert when these are offered (further advice about this should be sought from the Speech and Language team).

The human contact and social interaction when assisting someone with eating and drinking provide both stimulation and comfort, all of which help to maintain quality of life for the person.

Feeding someone often takes a considerable amount of time and skill, and the quality of relationship between the feeder and the person being fed has a huge impact on food intake.

Seeing a person eating less and less can be very distressing and many relatives wish to do all they can to help their loved one. However it is important to be aware that despite all the above interventions it may not be possible to maintain nutritional health for a person with swallowing difficulties because of the effects of the disease.

Tube feeding

If tube feeding is being discussed it is important to consider the following:

- What are the person's wishes?
- Is tube feeding really in the best interests of the person?
- Will the benefits of human contact be lost if the patient is tube fed?

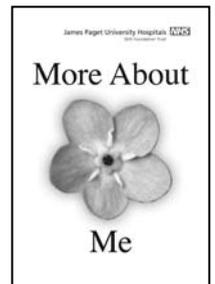
You should be given the opportunity to discuss these points further with all relevant health care staff.

Nutrition

For further nutritional advice and guidance, please contact a member of staff or visit www.jpaget.nhs.uk/departments-services/departments-services-a-z/dietetics/

What are we doing at the James Paget University Hospital:

- Red tray and jug – visual prompts for staff to ensure patients receive encouragement and assistance at mealtimes
- More About Me booklet – describing patient's preferences and choices
- Picture Menus – allowing patients choice
- Mealtime Volunteers to assist and support patients at mealtimes
- Protected mealtimes – allowing patients time to eat and creating an environment for an enjoyable mealtime
- High tea menu option – finger foods, which includes smaller menu portions
- Patient information leaflets relating to diet, poor appetite, support and guidance
- Carers support network available.



Medication



If a person is having difficulty swallowing medications, the doctor needs to know about this so that he/she can review the patient's medications. At this time it can be appropriate to stop some which are not essential for relief of symptoms.

For essential medications the doctor may consider changing medications to the following:

- Liquid, dispersible or soluble medications
- An alternative route of administering the medication e.g. skin patches or continuous subcutaneous infusion (syringe drivers) can be considered.

The law

As a relative or carer, unless you hold a relevant lasting power of attorney for personal welfare you cannot legally consent to any treatment on behalf of that person.

The law also makes it clear that while patients have the right to refuse certain treatments (such as tube feeding) in advance, they do not have the right to insist on certain treatments (such as tube feeding) if the health care professionals looking after them do not consider that the treatment will be of benefit to them.

The treating doctor will talk with the family and/or carers and make a decision in the best interests of the patient.

End of life

You may be very concerned that as food intake diminishes, the person will be feeling terribly hungry and thirsty. However, there is growing evidence that people at the end of life do not really suffer from hunger and thirst and that they can gain comfort from very small amounts of food and fluid. In the same way most people do not need fluid given via a drip to keep them comfortable at this time either.

Please do not hesitate to contact a member of the Palliative Care Team if you would like to discuss in more detail on 01493 452804

Further advice and support:

Dementia Liaison Nurses	01493 453231
Dietetic and Nutritional Advice	01493 452381
Speech and Language Therapy	01493 453164
Family carer lead (Louise Hamilton Centre)	01493 453100
Palliative Care Team	01493 452804
Safeguarding Vulnerable Adults Trust Lead	01493 452231
Learning Disability Lead	01493 453732
Alzheimer's Society	0300 222 11 22
www.alzheimers.org.uk	

Age UK Norfolk 01603 787 111
For general enquiries email info@ageuknorfolk.org.uk
For an advice query email advice@ageuknorfolk.org.uk

Age UK Suffolk 01473 359911
Email office@ageuksuffolk.org
For information on local services and support for older people in Suffolk contact our information centres or email: enquiries@ageuksuffolk.org

This leaflet has been adapted with kind permission from the Peterborough Palliative Care in Dementia Group –

A practical approach to palliative care for people with dementia – December 2010

Difficulty Swallowing: A practical guide to food, fluid and medication in advanced dementia and end of life for relatives and carers.

Written by Alison Smith, Specialist Dietitian and Keri Morrow, Specialist Speech and Language Therapist, Peterborough Palliative Care in Dementia Group - December 2010

Endorsed by:

- Suffolk Family Carers Focus Group
- James Paget University Hospitals NHS Foundation Trust
 - Palliative Care Team
 - Nutrition and Strategy Steering Committee
 - Dementia Liaison Team



James Paget University Hospitals **NHS**

NHS Foundation Trust

Courtesy and respect

- A welcoming and positive attitude
 - Polite, friendly and interested in people
 - Value and respect people as individuals
- So people feel **welcome**

Attentively kind and helpful

- Look out for dignity, privacy & humanity
 - Attentive, responsive & take time to help
 - Visible presence of staff to provide care
- So people feel **cared for**

Responsive communication

- Listen to people & answer their questions
 - Keep people clearly informed
 - Involve people
- So people feel **in control**

Effective and professional

- Safe, knowledgeable and reassuring
 - Effective care / services from joined up teams
 - Organised and timely, looking to improve
- So people feel **safe**



The hospital is able to arrange for an interpreter to assist you in communicating effectively with staff during your stay through INTRAN.

If you need an interpreter or a person to sign, please let us know.

If you require a large print version of this booklet, please contact PALS on
01493 453240