1 Learning Disabilities and Choking

This report was written by The Group on behalf of Hampshire Safeguarding Adults Board.

The Group: This is a group of professionals working in Hampshire for the Council, NHS, the Police and several other organisations. The Group met to discuss how to keep people safe from choking.

The Group was worried that in Hampshire 5 people with learning disability died from choking.

The Group saw that people with learning disability were at greater risk of choking than other people.

Reports showed that some services did not give good care to people with learning disability.

The Group wanted to make sure that people were safe and not at risk of choking. The Group wanted services to:

- ask for advice from GP’s and people working in Health
- find out who was at risk of choking
- train staff on risk of choking
- choose good supported homes for people to live in
- report any incidents of choking
- give information for everyone on the risk of choking
2  Choking incidents in the UK

The National Patient Safety Agency (NPSA) said that there were many incidents of choking between 2004 – 2007. These incidents mainly happened at mealtimes. The NPSA has advice on their website to help staff look after people with a learning disability.

Department of Health were looking into how people died in one part of England. Improving Health and Lives Confidential Inquiry checked the causes of death that could be prevented. They said that some deaths were caused by solids or liquids going down the wrong way in the lungs, and (or) epilepsy.

The Group looked at stories in the papers about people with Learning Disability who choked and died in care homes. The Group looked at these stories and found that:

- People died when the carers were not looking after them.
- First aid was not used properly when the person was choking.
- Staff were not following the care plans for eating and drinking.
- People who were at risk of choking were not protected from that risk.
What causes people with learning disability to choke?

**Dysphagia:**

This means difficulty with chewing and / or swallowing. This could cause food and drink to go into the lungs causing coughing, spluttering or choking.

A Speech and Language Therapist can check the way the person eats and drinks and can give advice on how to make chewing and swallowing safer.

**Bad teeth and gums:**

Many people with learning disability have cavities in their teeth, missing teeth or unhealthy gums. This causes them pain and makes chewing more difficult.

**Behaviour:**

People can choke if they put too much food in their mouth or eat too fast. People can also choke if they put non-food things in their mouth like paper or plastic. This is called Pica.

**Medication:**

Some medicines have side effects that can make chewing and swallowing unsafe like medicine for mental health and epilepsy. Staff must know how medicine affects people so they can help them eat and drink safely.

**Self-harm:**

People can choke if they place something in the back of their throat on purpose to harm themselves.
4 Commissioning and Monitoring Care:

Wider Commissioning:
Local authority and health services are responsible for making sure there are enough services to support people who have difficulties with eating safely.

Providers:
They are the groups of carers who offer to look after people with disabilities. They look after people in their own homes or in group homes.

Providers must make sure that staff are trained to support the person with their individual needs.

The Care Quality Commission (CQC):
They are the organisation that checks that providers are good at meeting the needs of people they support.

The government asked GPs to do health checks for people with Learning Disabilities. There is a guide for GPs on how to complete these annual checks.

Annual Health Checks:
The GPs are checking people’s health every year to find out if they need any treatment. This includes checking if they have a risk of choking or need dental treatment.

In Hampshire the NHS is making sure more people have their health checked every year. Staff called Health Facilitators are helping GPs to know about choking risks.
Social workers and NHS staff should assess the person and check if they are at risk of choking.

Social workers must find a provider who is good at looking after the person and keeping them safe. The social worker must check that the provider is doing a good job and that staff have good skills and information on how to keep people safe from choking.

Every person must have a care plan to tell staff how to look after them. A Speech and Language Therapist must assess if the person has dysphagia and tell staff about any risks and how to help keep the person safe.

Providers must help the person in their care to visit the dentist for a check-up. The social worker must check in the annual review that the person has a care plan with a risk assessment. They must also check that staff are trained and are following the care plan.

**Recommendations:**

- GPs should complete an Annual Health Check.
- There should be enough Speech & Language Therapists in the service.
- Every person with learning disability should be helped to visit the dentist regularly for a check-up.
- Social workers should check that the person has dental checks.
- Providers should follow the care plan of the person who has dysphagia.
5 Assessing Risk of Choking:

Consent to risk assessment:

People with a learning disability must agree to be assessed. NPSA have a form to tell people about the assessment and how they can say they agree.

Risk assessment and Dysphagia:

There are checklists that could show if a person has difficulty with eating and drinking.

The GP should check the person if they had choked. The Speech & Language Therapist will need to check if the person has dysphagia. They must give staff advice on how to help the person eat and swallow safely.

Risk assessment and behaviour:

Some people have difficult behaviours like eating non-food items or trying to choke themselves. Those people will need an assessment for their behaviour by the learning disability services. Services should offer help around those behaviours.

Recommendations:

✓ The Person must agree to be assessed.
✓ Refer the person to the GP or Speech Therapist for advice.
✓ Support staff must follow care guidelines.
✓ The person might need an assessment of their behaviour.
6 Mental Capacity Act and Advocacy:

**Mental Capacity Act**

This is a law to say that every person can make their own decisions and people can help them by making things easier to understand. If a person has a disability that makes it hard to make decisions, then others must make sure the person is safe and healthy.

Providers must help people understand the risk of eating certain food that could be unsafe. Providers must record decisions of a person who has capacity to choose food they want, even though it could cause them harm.

**Advocate:**

An advocate is somebody who helps a person have their wishes and views heard.

An advocate should help the person make decisions about what they want to eat. An advocate can help the person understand the risks of choking and help them say what they think and discuss it with the carers.

**Independent Mental Capacity Advocate, IMCA:**

This is a special advocate who helps people who do not have the skills to make decisions. An IMCA will get together with the doctors, family and carers to decide the right care plan for the person in their best interest.
Assessments and care plans should be updated if the person’s needs change. A person’s care plan and any decisions made for them must be checked regularly for any changes.

If the carers cannot agree on a decision in the person’s best interest, The Court can decide on what is best for the person’s health and safety.

When a person is at risk of hurting themselves if they go into some areas of the house like the kitchen, staff must apply for a law called Deprivation of Liberty Safeguard (DOLS).

**Recommendations:**

- If the person is at risk of choking they may need an assessment of their mental capacity.
- If the person’s freedom needs to be restricted staff need to apply for a Deprivation of Liberty Safeguard (DOLS).
- An advocate can help the person to understand their care plan.
7 Developing care plans for each person:

A person’s care plan must give clear information on how to make meal times safe and enjoyable.

Staff must know how to support the person to sit up and slow down when eating.

Staff also must know how to prepare meals that are safe for the person.

Some support staff said they felt that they did not have enough time to read or review the person’s care plan for eating and drinking. The change in support staff makes it harder.

Good ideas and good examples:

- Meal time place mats that show what a person can eat safely and how to support them at meal times.

- Examples of drinks to show and explain to staff how to make a person’s drink safer by adding the right amount of thickener.

Recommendations

- Carers and support staff must take part in the eating and drinking care plan.

- Support staff must understand what could go wrong if the care plan was not followed correctly.

- A person’s care plan needs to be reviewed every 6 months
8 Training and Health Information:

Training for staff:

Providers must make sure all staff are trained on how to support people with learning disabilities.

Hampshire County Council offers a service that gets information on what training providers and staff need. This group is called PaCT (Partnership in Care Training). They arrange training courses for staff and also offer information on their website.

First aid Training:

The group suggest that all staff have training in first aid. All staff must know how to spot that someone is choking and how to give first aid treatment. Staff must be trained on how to help remove what is in the person’s throat and blocking their airway.

Training for everyone:

St John’s Ambulance offer training for anyone who wants to learn about first aid. The British Red Cross also offer a course on Emergency Life Support.

Health Information:

There is a lot of information on the internet on food choice and eating well. There’s information on health action plans, oral health and meal planning. All that information is in easy read leaflets and can be found on www.easyhealth.org.uk and www.cwt.org.uk
Raising Awareness:

The Group want more carers to know about difficulties with eating and drinking. The Group want carers and support staff to have good information on:

- Knowing how to spot that a person has difficulty with swallowing
- How to help someone who is choking
- How to refer a person for an assessment by a Speech and Language Therapist
- How to support a person to eat and drink safely
- How to get help with checking the person’s capacity.

All groups of staff supporting a person should have good skills and knowledge. This should include managers, support staff, caterers and chefs. This will help them check for signs of difficulties like chest infections, weight loss and refusal to eat.

Recommendations:

- New staff should have training on choking and first aid.
- First aid trainers must include how to respond to choking in their training.
- Staff need to practise how to respond to choking in their first aid training.
- Speech and Language Therapists must offer training to support staff on eating and drinking difficulties.
- All care services should know about the information on the NPSA website.
- There should be more information for everyone on the risk of choking.
9 Going into Hospital:

**Hospital Passports:**

A hospital passport describes how the person communicates, using speech and non-verbal communication. This should include how the person expresses pain and discomfort. In Hampshire all services are using hospital passports. A person must agree to share their information with the hospital staff.

**Sharing Information**

A “Hospital Passport” must be ready for a person going into hospital to share information about their health with hospital staff.

In Hampshire most health staff use a form called “Admission to Hospital Information”. This form has information about the person’s health and includes a section on eating and drinking.

The Group want the form to be revised to check for the risk of choking.

**Health Facilitator:**

A Health Facilitator helps a person get a good service when they are going into hospital. They can tell hospital staff about the person’s capacity and give them training on the person’s needs. They can give the person easy read information to help them understand their condition and what will happen in hospital.

Health facilitators need to check if the person is at risk of choking. They need to share information with hospital staff to make sure the person is safe while in hospital.
Recommendations:

- Every person should have a hospital passport with information about their health.
- The hospital passport should include any risk of choking.
10 Reporting Choking Incidents:

Support staff must tell the right people if someone chokes. The GP must check the person’s health and refer them for more assessments or tests.

The Social Worker must check the person’s social care assessment to check if the person is still safe in their home.

The provider must tell the Local Authority and the NHS team if the person suffered harm so they can do an investigation.

Role of the Police:

The Police will investigate if a person dies from choking to check that there was no neglect, such as the person died because their care plan was not followed.

Role of the Coroner:

The Coroner:

This is the person who finds out the cause of death when someone dies.

The Coroner will write a report about the cause of death and send it to the organisations. This will help organisations who want to prevent any further deaths.
**Recommendations:**

- All choking incidents must be reported to the right people.
- The Police, CQC and the Local Authority must be told if someone is seriously harmed or dies.
11 Conclusion:

- The Group know that death from choking is a serious problem.
- The Group wants the Department of Health to get more information on the numbers of people with Learning Disability who have choked and died in the UK. This will help services understand how big the problem is.
- The Group have put together ideas for preventing more deaths happening as a result of choking.
- People with Learning Disability have the right to make their own decisions. They must be helped to understand their choices and the risk of choking.