

**Reducing the risk of choking for
people with a learning disability**
A Multi-agency review in Hampshire



Hampshire Safeguarding Adults Board
Multi-agency partnership

Reducing the risk of choking for people with a learning disability

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Executive Summary

This report is aimed at people who are working with those who have a learning disability, in the role of commissioners or providers of services.

The report has been produced on behalf of the Hampshire Safeguarding Adults Board by a multi-agency group. This group comprised of individuals with specialist knowledge from across Hampshire and included the involvement of representatives from Southampton, Portsmouth and the Isle of Wight. The Group focused on this issue following five cases of choking resulting in death, in learning disability clients reported to Hampshire County Council between 2005-2010.

In this report, we have sought to understand why people with a learning disability are at greater risk of choking and to look at what we in Hampshire can do to improve outcomes for people who are at risk of choking, in any care setting. A number of recommendations are made at the end of the report as a result of the findings which are all based on common sense and good practice.

These recommendations cover a wide range of issues including understanding of causes of choking; recognition of choking risk; emergency response to someone who is choking; training for staff; commissioning placements and supporting people to keep healthy. Throughout the course of this work we have become aware that there is no national collection of data in relation to choking deaths and no clear understanding of the issue. The National Patient Safety Agency carried out work in this area in 2007 but this data is now five years old.

The Group has therefore recommended a number of simple strategies that providers can use to identify individuals at risk of choking, ensure that they have access to dental and medical checks to keep healthy and that their staff are trained to address choking risks, both from the perspective of the rights of the individual but also in terms of a first aid response if a person does choke. In addition, we have recommended that commissioners ensure that appropriate placements are found with providers who can work with individuals to manage their risk and also that sufficient speech and language therapy resource is in place in the community to meet the needs of those service users who require specialist assessment.

Finally, as part of this work it has become clear that there is no national collection of information about choking in learning disability clients and yet we have discovered it is a regular cause of death amongst this group. The Group would therefore recommend that Safeguarding Adults Boards request that the Department of Health make arrangements to collect this data in order to understand the scale of the problem and seek to address it.

I Setting the Scene: Learning Disabilities and Choking

People with a diagnosis of learning disability are well known to be at higher risk of choking than other people and there is much research evidence to support this, for example, Thacker (2007), Samuels (2006). This is due to several factors including problems with chewing, difficulty swallowing (dysphagia), behaviours such as bolting food or pica (eating inappropriate and non-food items) and the effects of medication.

These difficulties can have a significant impact on a person's health, resulting in problems such as aspiration pneumonia and frequent upper respiratory infections, undernutrition and dehydration (Harding, 2010). In the most extreme cases, a piece of food (or non-food item) can obstruct the airway and lead to death.

There has been national concern regarding the care of those with a learning disability - the *Death by Indifference* (Mencap 2007) report describes what it calls 'institutionalised discrimination', which results when organisations fail to make changes in the way they deliver services to take account of people's differing needs. In addition, the *Six Lives* report (PHSO 2009) questioned commissioning and provision of services, stating:

"The findings of our investigations pose serious questions about how well equipped the NHS and councils are to plan for and provide services tailored to the needs of people with learning disabilities".

Since the *Six Lives* report, Mencap have identified a further 74 people with a learning disability (Mencap 2012) who have died as a result of institutional discrimination. The report cites poor communication, lack of basic care and attention, and a failure of services to meet the different needs of people with learning disabilities as reasons for the high numbers of deaths.

In Hampshire, it was noted that there have been five deaths between 2005-2010 resulting from a choking incident in a person with a learning disability. All of these individuals were living in a supported environment and all cases had been reviewed in order to determine the learning for services. In looking at all the five cases together, it was noted that there were a number of similarities so a decision was made to bring the issue of choking in people with a learning disability to the attention of the Hampshire Safeguarding Adults Board for action.

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In response, the Hampshire Safeguarding Adults Board established a multi-agency review (The Group) to review the five deaths and explore and identify areas of service that could be improved. It was recognised that the issue is pertinent to a range of stakeholders, hence the multi-agency approach. The Group – which included representation from Southampton, Portsmouth and the Isle of Wight areas - met several times during 2011 and work streams were established to review particular areas of practice. Membership of the Group and other people who contributed to this review in person and by correspondence can be seen at Appendix 2.

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There were a number of work stream areas identified during the review which were seen to influence the successful management of risk of choking, including:

- Recognition of people who may be at risk of choking
- Appropriate referral to health professionals for advice and planning
- Care staff training around the recognition of risk, mental capacity assessments and best interests decision making, and First Aid to be given when someone chokes
- Effective commissioning and monitoring of placements for people who are at risk of choking
- Consistent reporting of choking incidents including application of safeguarding processes
- Information for the public.

The aim of the review was not to do a full literature search or undertake primary research, but rather gain a broader understanding of prevalence and causes of choking and identify any issues in practice. The Group consulted colleagues and looked at what was happening elsewhere in the UK around choking management and prevention. The review considered people in all care settings.

The Group worked on the assumption that the ideal situation is where parents or regular carers have a full understanding of the person with a learning disability - their needs, wishes/choices and the risks inherent in living their lives – and who take action to minimise their risk of choking.

2 National Picture of Choking Incidents in People with a Learning Disability

The Group tried to establish national figures for premature deaths of people with learning disabilities caused by choking, but discovered that there is no national data collection, but rather several bodies collecting data.

2.1

National Patient Safety Agency

The National Patient Safety Agency (NPSA) receive reports mainly (although not exclusively) from healthcare settings. The NPSA received 605 reports of choking-related incidents involving adults with learning disabilities between 30 April 2004 and 30 April 2007. The majority of these incidents (58%) took place at mealtimes. Incidents occurring in residential care homes accounted for 41%, and 58% took place within inpatient and assessment services. The remainder occurred in public places. As a result, the NPSA produced a comprehensive set of tools to help staff support people with a learning disability and plan care around eating and drinking. It is not our intention to reproduce any of the NPSA work here and these resources may be found on the NPSA website: www.nrls.npsa.nhs.uk/resources/?entryid45=59823

2.2

Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD)

Bristol University is leading this ongoing inquiry which is funded by the Department of Health and aims to improve the health and wellbeing of people with a learning disability by carrying out an inquiry into cause of death. The Confidential Inquiry began data collection on 1 June 2010. In the first year the team were notified of the deaths of 119 people with learning disabilities that met the criteria for investigation, occurring within the Gloucester and Avon area of England. The Inquiry will continue into 2012 in the Gloucester and Avon area. For an interim report see: www.bris.ac.uk/cipold/documents/short-interim-report.pdf;

2.3

Improving Health and Lives Report

Glover (2010) looked into the cause of death as cited on death certificates of people with learning disabilities who died in England between 2004 and 2008. He suggests that two, possibly preventable, causes of death stood out as particularly important because they were common and affected most groups of people with learning disabilities. They were problems caused by solids or liquids 'going

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down the wrong way' (14% of deaths) and epilepsy or convulsions (13%). The report suggests that services looking after people with learning disabilities should pay particular attention to these preventable causes of death.

2.4

Reporting from other Local Authorities

Other Local Authorities were asked, via the Association of Directors of Adult Social Services (ADASS), to provide the Group with critical incident reviews or serious case reviews of death or serious harm of people with a learning disability by choking so that we could see if there were wider lessons that could be learned. The response rate was low. The Group believe that under-reporting of incidents is an issue.

A serious case review reported to us by a Local Authority took place following the death of Adult A, who choked to death on a pickled onion provided by care staff at the residential care home where he was living in 2007. Adult A was 27 and his care plans showed that food should be cut up as he was at risk of choking. The home was experiencing staff shortages and the carers on duty were volunteers whose first language was not English.

(Brazier, 2009)

2.5

Findings from the media

A number of news stories were identified in relation to the issue of choking, for example:

September 2011

A 54-YEAR-OLD man with severe learning disabilities died after choking on a pork pie, an inquest has heard.

A Coroner's Court heard that when his lunch was brought to him on a tray, 'C' lunged forward, grabbed a pork pie and stuffed it into his mouth. Almost immediately afterwards he grabbed part of a ham sandwich, that was also on the tray, and stuffed it into his mouth. The manager said "C was able to eat and drink food by himself and use cutlery, he often ate too quickly and had to be told to slow down. He sometimes put too much into his mouth and his food had to be cut up into small pieces."

A verdict of accidental death was recorded.

(Anonymous 2011)

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June 2011

COUNCIL failures created a “cavalier” attitude in a care home where a 26-year-old man with learning difficulties choked to death, a review has found. Barnet Council have been slammed for not having a proper contract with the home and failing to monitor the service.

The serious case review found there had been four incidents in the weeks before his death where Jesse had choked, but the risks to him were downplayed by staff at the home and on the day of his death, he was left in the hands of two unqualified staff members, one working with a false name and false certificates. Jesse stole a ham sandwich from another resident’s lunch, put it in his mouth and choked to death on a chunk of food the size of a golf ball unobserved by care home staff.

The company running the home was fined £250,000 in 2009 and has since closed the home.

Councillor Sachin Rajput, Barnet’s cabinet member with responsibility for Adult Social Care said: “It is clear that at the time of Jesse’s death there were clear failings in the centre in which Jesse was living and in how Barnet managed its relationship with that home.”

(Royston 2011)

Further media reports can be found at **Appendix 3**.

It was noted that the language used in the media reports was judgemental, often making inappropriate references to the individuals being ‘obsessed’ with food and ‘snatching’ or ‘stealing’ food from the kitchen of their home or from other residents. The Group recognised that for some people, food may be the main pleasure of life and when they are left unsupervised, hungry and bored, behaviour such as taking food from the plates of others or from an open kitchen is highly likely.

It was also noted that there were several other patterns emerging from the media reports:

- a lack of carer supervision evident at the time of the choking incident
- the First Aid response to a person choking was inconsistent
- care plans around eating and drinking were not followed
- people known to be at risk of choking were exposed to risk.

These issues were included for consideration as part of the work done within this review.

3 What Causes People with a Learning Disability to Choke?

3.1

Dysphagia

Dysphagia is the term used to describe eating or drinking disorders. Dysphagia may be due to a number of causes: mechanical difficulties in dealing with food or drink in the mouth such as difficulty with mouth movements, chewing and preparing food for swallowing; and difficulty with swallowing. Dysphagia can lead to food or drink entering the lungs instead of the stomach, causing choking, coughing and spluttering.

A Speech and Language Therapist will be able to assess the cause of the dysphagia and advise on the best treatment for the individual, which may include modifying food and drink consistency, altering the person's position during mealtimes, pacing the meal and helping the person slow down, and use of specially adapted cutlery.

The National Patient Safety Agency have produced a guide called 'Ensuring safer practice for adults with learning disabilities who have dysphagia' which is available online at: www.nrls.npsa.nhs.uk/resources/?entryid45=59823

3.2

Poor oral health

One in three adults with a learning disability and four out of five adults with Down's Syndrome have unhealthy teeth and gums including untreated decay and missing teeth. This can result in a number of behaviours such as loss of appetite, unwillingness to participate in activities, sleeplessness, irritability or self harm.

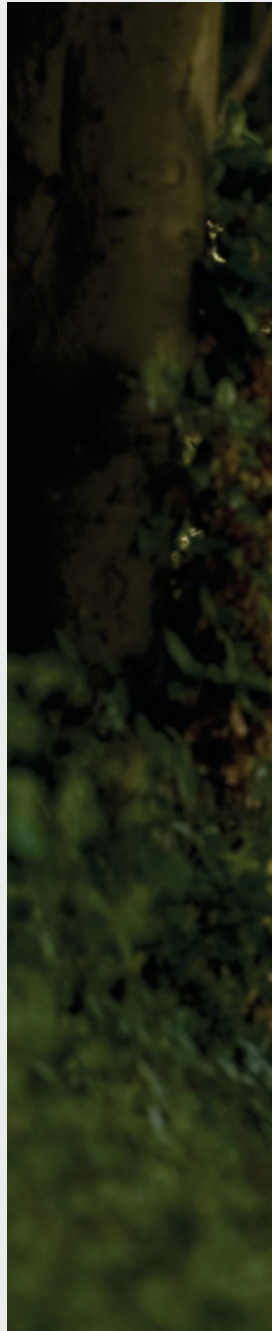
(Crawley 2007)

Oral Care Guidelines for people with learning disabilities have been produced by The British Society for Disability and Oral Health (2001) and are available to care services providing for people with a learning disability.

3.3

Behaviour

Choking which is not as a result of dysphagia, can be as a result of behaviours such as cramming or bolting food. For example, when eating, a person may push large amounts of food into their mouth which causes them to choke. A person may also place non-food objects into their mouth which causes them to choke – see 3.4 'Pica'.





'In long-stay hospital wards it used to be common for people to eat their food very quickly in an attempt to ensure no-one else ate it, especially if they were often hungry and had no access to snacks. Some people with learning disabilities in residential care still have this behaviour and it has been linked to increased risk of asphyxiation and choking. Risk of choking can also be associated with bolting food – for example, in people who take food from someone else's plate and bolt it to avoid detection'.

(Crawley 2007)

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3.4

Pica

Pica is the term used for eating non-food items such as plaster, coal, faeces, soil or cigarette ash. It is not normally seen in the general population (except occasionally among pregnant women and children aged 1-6 years), has been associated with severe disabilities, schizophrenia, depression, large group living, younger age and male gender, autism, dehydration, and swallowing difficulties.

(Crawley 2007)

3.5

Medication

Medication which alters levels of alertness (e.g. some antipsychotics and drugs given for the control of epilepsy), those which alter muscle tone or coordination (such as some antidepressants) and medicines which delay the swallowing process or increase salivation (such as some anti-psychotics) can all impact on swallowing function.

(Crawley 2007)

Some drugs suppress the gag reflex, so if something 'goes down the wrong way' the person is less able to cough it up. This has implications for the care of people treated using these drugs. Staff and carers need to be aware of the effect of suppression of the gag reflex and of the appropriate action to take if choking occurs.

3.6

Deliberate Self-harm

Choking may occur as a result of intentionally placing something into the mouth or back of the throat to induce choking as a means of self harm including suicide.

4 Commissioning and Monitoring Care

The Group considered commissioning in relation to two separate responsibilities. Firstly wider commissioning of services by the health service commissioners and local authority bodies. Secondly, local commissioning carried out by the social service and health staff who undertake the assessments and find the right placements for the individuals, where this is necessary.

4.1

Wider Commissioning

It is the responsibility of the local authority and health service commissioners to ensure that they have in place a market of providers that are able to deliver care to people with a learning disability who are at high risk of choking.

Provider Services are regulated by the Care Quality Commission and are required to meet a number of essential quality outcomes in order to register to provide services. As part of this arrangement, providers must only accept clients where they are clear that they can meet their needs. This includes the need for providers to ensure that their staff are appropriately trained to deal with issues arising from these individual needs.

Commissioners must therefore ensure that all contracts with provider organisations outline the same requirement.

In addition, the Group considered the provision of annual health checks for people with a learning disability as a way of ensuring that there was an annual assessment offered.

In 2009, directions were published by the Department of Health requiring Primary Care Trusts to offer GPs in their area the opportunity to provide health checks for people with a learning disability and these were introduced as a Directed Enhanced Service (DES). Since that time significant progress has been made in increasing access to annual health checks across PCTs and Strategic Health Authorities in England (Robertson 2010). Robertson suggests that a wide range of health issues are being picked up at annual screening. These include weight loss and a need for dental treatment which could indicate that a person is at risk of choking.

The national figure for the number of adults with a learning disability receiving an annual health check in 2010-11 is 49%. (Emerson, 2011). In the South Central region, the number of adults with a learning disability who received an annual health check in 2010-11 was 37%. As at early 2012, work is being done to increase the number of health checks in

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Hampshire through the South Central Strategic Health Authority, the Primary Care Trust and the emerging GP Clinical Commissioning Groups.

The Health Facilitators (see section 9.2) in Hampshire are involved in supporting GPs by providing training around the DES and will target GP practices that are not yet signed up to the DES. The Cardiff Health Check Template for DES is not specifically looking at choking and dysphagia, but does ask about cough/wheeze and weight loss. The Health Facilitators now highlight additional risks to raise awareness of choking risk to GPs during the training.

The Royal College of General Practitioners have published their report 'A Step by Step Guide for GP Practices: Annual Health Checks for People with a Learning Disability'. This includes a reference to eating and drinking difficulties (Houghton 2010). However Speech and Language Therapists in Hampshire reported that they have not received any referrals to their service following a GP health assessment.

The NPSA has produced a learning disabilities assessment tool and protocol for GPs which can be found at Appendix 4.

Through the course of this review, it became clear that there is a key role for community Speech and Language therapy services in supporting commissioners, providers, GPs and other health staff in identifying choking issues for learning disability service users and care planning with them to mitigate against these.

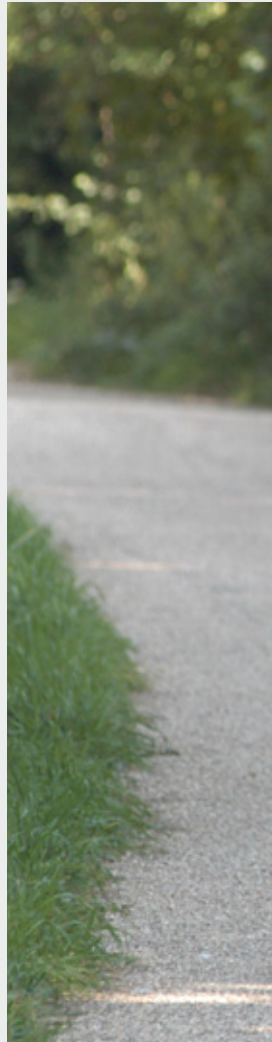
However, it was discovered that the Speech and Language therapy resource in the community in Hampshire is varied. It is clear that this resource is vital to support those who provide care for learning disability clients, therefore the Group recommend that sufficient resource is ensured by commissioners for this purpose.

The South Central Strategic Health Authority in February 2012 have sent out a safety alert to all providers and commissioners of learning disability services, requesting a full review of current policies and procedures in relation to choking and this can be seen at Appendix 5. This letter supports the work carried out during this review.

4.2

Local commissioning and monitoring

The key approach to commissioning services for people at risk of choking (or with any other health problem), as stated above, should be that the care must be provided in a setting that can meet the specific needs of the individual. It is recognised that many people with a learning disability with high support needs receive integrated health and social care in their own homes.





In order to deliver this, prior to any placement, a social worker and health professional should undertake a full assessment to identify the care needs of the individual, which should include an assessment of swallowing and risk of choking.

Once this assessment is complete, the social worker and health professional will then make a judgement as to what sort of care setting is required by the person. This assessment will be shared with any prospective care provider who would be required to confirm whether they can meet these specific needs.

If the provider agrees that they can meet the needs identified, the social worker should satisfy himself or herself that this is the case, which would include making sure that if the person is at risk of choking, staff at the placement have the training and knowledge to minimise the risk and can deal with an emergency situation if the person should choke.

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A clear care plan must be in place for the individual and should be constantly monitored by the care provider and the risk re-assessed as the needs of the individual change, for example, a change in medication. Staff must be trained and competent to respond to the care plan.

The care provider should ensure that all people who show the symptoms of dysphagia are screened and receive a professional assessment. As there are many different causes of dysphagia, an assessment by a specialist is required to determine the type and the level of associated risk. This would normally be conducted by a Speech and Language Therapist. If a person has experienced a choking episode in a placement, it would be an expectation that the care provider would liaise with the person's GP. If a person were to choke and suffer harm, it would be expected that the care provider would report the incident. (see section 1)

Poor oral care is a key contributory factor in choking. As outlined in section 3.2, people with a learning disability are more likely to have unhealthy teeth and gums. Care providers have a clear responsibility to ensure that people in their care attend a dentist. If the individual requires adaptation and support the dentist can refer to the specialist dental service in Hampshire. GPs can also refer. Carers must make every effort to ensure that people in their care attend dental appointments and checking attendance should form part of the annual review of the individual.

It is expected that the social worker will review the individual in the placement on an annual basis. At any review, the social worker would need to be satisfied that the care plan and risk assessments are up to date and that family is involved and access to advocacy has been arranged, where this is relevant. In addition, the social worker may look at the staffing rota and level of training to assure themselves that the service user is receiving the services commissioned.

Recommendations

Adults with a learning disability should be supported to take up annual health checks.

Health commissioners ensure that there is sufficient Speech and Language Therapy resource within the community to respond to requests for assessment of those Learning Disability clients, identified by service providers, as at risk of choking.

Social workers, as part of their annual review of placements, must check that individuals are receiving dental checks.

All Primary Care Services in Hampshire are sent the NPSA Learning disability Dysphagia Protocols for GPs. (Appendix 4)

Individuals with a learning disability should be supported to attend a dentist for regular check ups.

5 Assessing Risk of Choking

It is, of course, impossible to prevent all choking episodes because any person of any age could accidentally choke at any time. However, when a person is at risk of choking for whatever reason, then steps must be taken to minimise both that risk and the risk of harm suffered if they do choke. As it is already established that people with a learning disability are at much higher risk of choking than the rest of the population, it would seem appropriate for those working with people with learning disabilities to assess the risks to each individual. Assessment of risk should include assessment against each potential cause of choking.

5.1

Consent to risk assessment

The consent of a person with a learning disability must be obtained before a medical investigation or assessment is carried out. The NPSA guidelines 'Ensuring Safer Practice for Adults with Learning Disabilities who Have Dysphagia' (2007), contain a consent form for Assessment of Eating, Drinking or Swallowing Problems for use with clients who have a learning disability. This can be found through the attached link and it is recommended for use by the Group: www.nrls.npsa.nhs.uk/resources/?EntryId45=59823.

5.2

Risk assessment and Dysphagia

The Group found that currently there is no standard local Hampshire assessment in place that indicates if a person is at risk of choking due to dysphagia. A simple choking assessment tool for use with all learning disability clients has been developed by Southern Health NHS Foundation and can be found at Appendix 6. If this assessment indicates that a risk of choking exists a referral should be made either directly to the GP or by contacting the Community Learning Disability (LD) Team who will be able to advise upon the appropriate referral route. For those clients with an existing diagnosis of dysphagia, or found to be clearly at risk of choking, the assessment found in appendix 4 can be used.

5.3

Risk assessment and behaviour

Some people with a learning disability may exhibit behaviours that challenge, such as putting non-food items in their mouth, swallowing non-food items or deliberately trying to choke themselves through self-harm. If this is the case, an appropriate multi-disciplinary challenging behaviour assessment is required, which may include a psychiatric assessment. This assessment can be achieved through referral to local learning disability services.

Recommendations

The consent of the person with learning disability must be obtained before any medical investigation or assessment is carried out. This consent – in relation to assessment of eating and drinking – can be gained using the form found at - www.nrls.npsa.nhs.uk/resources/?EntryId45=59823

All services providing for clients with a learning disability should use an Eating and Drinking Difficulties Screening Tool (Appendix 6), which will indicate whether a choking risk exists and a referral to the GP is needed.

All services providing for clients with a learning disability, who have a known risk of choking, should use the documentation found at www.nrls.npsa.nhs.uk/resources/?EntryId45=59823 in order to ensure the appropriate referrals are made.

All services providing for clients with a learning disability should ensure that they follow the instructions provided by the Speech and Language Therapist following an assessment.

All services providing for clients with a learning disability who are at risk of choking, as a result of challenging behaviour or deliberate self-harm, should refer the individual to the multi-disciplinary team for a formal assessment.

6 The Mental Capacity Act and Advocacy

6.1

The Mental Capacity Act 2005

The Mental Capacity Act 2005 confirms an individual's right to make decisions for themselves where they have the mental capacity to do so. The Act seeks to ensure that people who lack capacity to make specific decisions for themselves are protected from harm that may arise from their lack of capacity, by allowing others to make decisions in their 'best interests.'

Where a person at risk of choking has the mental capacity to make unwise choices, they may choose to make a decision to eat food they enjoy, even though they know it may cause them to choke. The Group recognise the difficulty this may cause for care providers, but in this case, a person's choice must be respected and all efforts made by the provider to ensure that they are able to deal with an episode of choking that may result from this decision.

The provider must record all discussions had with the individual and others to establish their choice in the matter of eating and drinking. In the event that a referral is made to a Speech and Language Therapist or the Learning Disability Health team for an assessment, consent should always be gained from the individual where mental capacity exists, and recorded. Decisions regarding the individual's choices are best captured as part of a care plan which reflects their wishes and choices in relation to eating and drinking to ensure all staff are clear when providing support to this person.

Where a person at risk of choking is suspected or known to lack the mental capacity to make decisions about the type of food they should eat, a formal Mental Capacity Act assessment must be undertaken to evidence this. Decision makers have a duty to act in the best interests of the individual and will therefore need to consult other people who could include anyone caring for the person, an advocate, an Independent Mental Capacity Advocate (IMCA), family carers and close relatives, and should draw up a care plan for the person, confirming arrangements in relation to eating and drinking for that individual.

It should be remembered that these assessments and decisions should be revisited following any change or deterioration in the health or behaviour of the individual.

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Care staff that subsequently follow the care plan will then be protected from incurring any liability should the person choke while eating or drinking.

Sometimes there may be conflicting concerns and a decision maker may be faced with carers or family members who disagree with the decisions reached, either with the person, or in their best interests. In this circumstance, it is up to the decision maker to weigh up the views of different parties and decide what is in the person's best interests. In the event of a significant dispute regarding the best interests decision made, efforts should be made to resolve it through discussion, negotiation or mediation. In the event of serious and irresolvable disputes about best interests, an application may need to be made to the Court of Protection for a decision about the person's welfare best interests.

It may also be necessary, in some cases, to prevent an individual from accessing any areas within a residential setting due to their behaviours and consequent choking risk. If this action is taken, it may result in a deprivation of liberty which would fall under the Deprivation of Liberty Safeguards and an application to the local Supervisory Body (Local Authority) under the Mental Capacity Act may be required.

6.2

Advocacy

The Group suggest that an advocate may be able to support decision making in the following ways:

- Support people to express and have their views and wishes heard and to access their rights as citizens.
- Gain an understanding of any expressed or previously stated views and wishes and of the person's rights and entitlements. If a person is not able to instruct the advocate themselves then skills in 'non instructed advocacy' are needed to gather an evidence base, from observation, from others who know the person well and from specialist advice.
- Present these findings to represent the individual in any decision making process. This work can be helpful when a staff team are resistant to an eating plan, and can be included in a best interests decision making process.

The advocacy task if a person has been assessed to be at risk of choking could be to seek to ensure they have access to information and are able to understand and express their views clearly. If the person lacks mental capacity the advocate must endeavour to ensure that the views and wishes of the individual are gathered from those

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who know them best, that the person's safety is promoted and that this is reflected within the process of decision making.

Advocates will make formal complaints and referrals to safeguarding processes if they witness poor or abusive practice.

Independent advocacy is commissioned for people with a learning disability across Hampshire. There are four specialist learning disability organisations and three generic advocacy organisations providing issues-based advocacy to individuals. Most organisations operate an open referral system; professionals, family relatives or the person themselves can request independent advocacy support. The Hampshire Advocacy Regional Group (HARG) signpost to local advocacy groups. www.hampshireadvocacy.org.uk/about-harg This link is to the HARG website.

All organisations publish their work via leaflets and websites and can provide support with understanding the role of independent advocacy. There may be a need for training for care staff and managers about advocates, particularly for people who lack friends and family including those in closed hospital settings.

Recommendations

If staff or carers identify that someone is at risk of choking from food or other objects in their mouth, a Mental Capacity Act assessment needs to be considered to support appropriate decision making. For more information, see Appendix 7.

If clients, as a result of their behaviours and the consequent risk of choking, are prevented from accessing areas within a residential setting then an application should be considered by the care provider to the Supervising Authority (Local Authority) under the Mental Capacity Act Deprivation of Liberty Safeguards.

If staff or carers identify that someone is at risk of choking, they must consider a referral to an advocacy organisation for an advocate to support the person with decision making in relation to eating and drinking plans.

7 Developing the Individual Care Plan

A person's individual care plan should provide enough information so that the caregiver understands what they need to do in order to support the person to eat and drink safely and minimise the risk of choking.

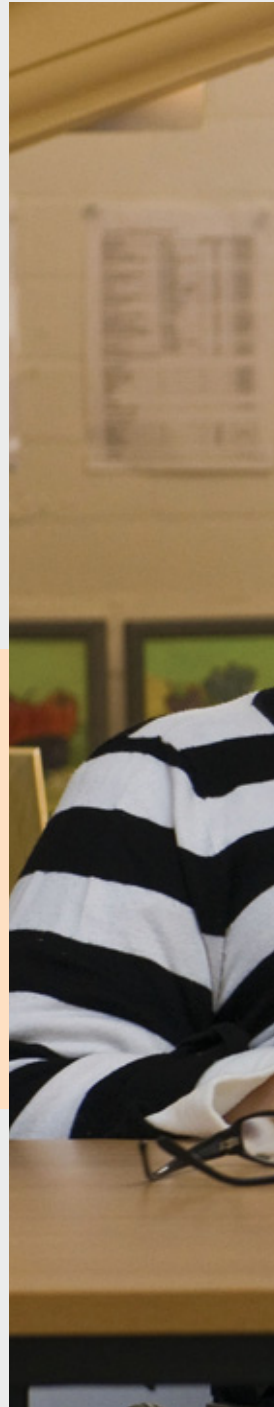
Harding (2010) describes key interventions that may be used to support someone with eating and drinking difficulties. These include: strategy management based on maximising motor skills; ensuring that a person's posture will reduce risk whilst eating and drinking; using techniques such as pacing, prompting and communication; modifying textures so that a person can manage foods safely; managing sensory skills that may affect food tolerance/intake and reducing behaviours that have a negative impact on the ability to acquire enough nutrition.

In interviews with 46 caregivers, Chadwick (2005) found that caregivers found some aspects of supporting people with learning disabilities to eat and drink difficult. Caregivers felt that they were responsible for modifying the consistencies of meals and drinks correctly, but appeared reluctant to accept responsibility for support guidelines such as prompting the person to take safe mouthfuls and slow down, or facilitating people to relax and concentrate on their meal, instead placing responsibility in the environment or employing organisation and blaming time pressures, staff turnover and insufficient time to review Speech and Language Therapy (SaLT) management strategies by caregivers.

7.1

Good ideas and good practice examples:

- Individualised placemats for people with learning disabilities are used at mealtimes in residential settings, day centres and clients' homes. Each mat is a piece of laminated A3 paper that is put on the table at mealtimes. It has the client's photo and pictorial reminders about whether food should be chopped up, blended or left in its natural state. The best seated position for clients is also shown, alongside details about what specialist equipment or cutlery is needed and what consistency their drinks should be: syrupy, custardy or pudding-like. The placemats provide reminders for carers and the clients themselves. (Duffin 2010)





- 'TIM' Tubes. (Thickness Indicator Model). The model is a set of five clear plastic tubes which look like egg-timers containing fluids of different thicknesses and was invented by the LD Eating and Drinking Group in Essex. (Ord, J. 2008) The idea is to demonstrate to carers the exact thickness of liquids needed for individual patients who have difficulty swallowing. Up to now, only written descriptions of the different thicknesses have been available. This project has won three awards for innovation in safety.

Reducing the risk of choking for people with a learning disability

Duffin (2010) suggests that staff can be imaginative when it comes to food, and describes how one resident's chocolate Easter Egg, instead of being withheld as the person could not eat solids, was melted down and made into chocolate mousse which the resident enjoyed.

Recommendations

All carers and staff should be involved in the care planning process for people at risk of choking, particularly those who will be implementing the plan.

Carers and staff should be aware of the consequences of not following an agreed eating and drinking care plan.

Care plans to support people at high risk of choking should be reviewed at least every 6 months or after any change in the person's health or treatment.



8 Training and health promotion

Training for staff

It is the responsibility of the service provider to ensure staff are trained so that they can meet the needs of the individual person with a learning disability who may be at risk of choking.

In Hampshire, there is a workforce development partnership between Adult Services and the private and voluntary adult social care providers. This is supported by a small team of Hampshire County Council staff called Partnerships in Care Training (PaCT). Their role is to gain an understanding of where training and management support is needed, through links with the Care Association and Commissioners of care services, or in response to trends in safeguarding concerns, or through the Quality Outcomes and Contract Monitoring group.

Support to providers from PaCT may be through formal courses, management development days, posting information on the Hampshire Adult Services website, signposting or one-to-one visits to providers.

8.1

First Aid training

Staff working in settings where there are people with a high risk of choking need to be aware of the catastrophic consequences that occur if the person chokes.

Because recognition of choking (airway obstruction by a foreign body) is key to a successful outcome, it is important not to confuse this emergency with fainting, heart attack, seizure or other conditions that may cause sudden respiratory distress, cyanosis or loss of consciousness. The Group suggest that all staff working with people who are at risk of choking should have mandatory training on the recognition of and First Aid treatment for choking.

The aim of First Aid treatment is to remove the foreign body that is blocking the airway. The Group suggest that each service user should have an individual treatment plan so that those who are wheelchair users or cared for in bed are treated by First Aid appropriate to their needs.

The National Patient Safety Agency recommend that regular practices or drills are carried out around resuscitation (NPSA 2008). In this case drills could be around a choking incident, so that staff know exactly what to do should choking occur.



8.2

Awareness Raising

The Group recognise that a greater emphasis is required to raise awareness of the risk of individuals choking and the steps that can be taken to reduce the risks.

One carer suggests that 'in the past, if people with learning disabilities started coughing and spluttering on their food it was just treated as normal' but that heightened awareness from training now means that more Speech and Language Therapist referrals are made. (Duffin 2010)

The Group suggest that awareness raising includes:

- recognition of signs and symptoms that may indicate a risk of choking
- emergency aid response to choking
- referral processes to Speech and Language Therapy or multi-agency team
- food preparation
- skills to support individuals at risk of choking with their eating and drinking
- planning care and support to meet individual needs and wishes
- application of the Mental Capacity Act 2005.

This could be achieved through a blended learning model that is not solely reliant on formal training but also embeds learning gained from day to day practice.

The Group have recommended a standard Training Matrix for caregivers of people with a learning disability, which may be found at Appendix 8, in order to support individuals who provide care to people with a learning disability to be thoroughly prepared for any choking episode.

Within provider services, Guthrie (2011) found that involving all the team, including senior management, care staff, catering staff and chefs as well as the service users in training and awareness raising about healthy eating meant adherence to the care plan was much higher. Because they have an increased awareness, all staff within this setting are now able to monitor for the warning signs of dysphagia, such as recurrent chest infections, weight loss, and refusal of food.

8.3

Training for the public

St Johns Ambulance offers free training to members of the public in its essential First Aid (Adult) course. The course lasts 2 hours and covers treatment of choking in adults. www.sja.org.uk/sja/training-courses/courses-for-the-general-public/essential-first-aid.aspx

The British Red Cross provide training for the public, there is a cost attached. For example, their 4 hour Emergency Life Support course cost, in 2011, £25.

8.4

Health Promotion initiatives

The Caroline Walker Trust (Crawley 2007) is an excellent source of reference and has information which explores the issues around food choice and eating well for people with a learning disability. They also provide practical information to support carers as well as guidance for policy makers, managers and catering staff around good practice. The publication 'Eating Well: Children and Adults with Learning Disabilities' is available at www.cwt.org.uk/pdfs/EWLDGuidelines.pdf. Easy Health www.easyhealth.org.uk provide leaflets and information on all sorts of health matters in 'easy-read' format. The website is part funded by Mencap and is supported by a charity called Generate. Other organisations are encouraged to add their own information to the website so that it can be available to all. Topics of relevance include healthy eating, oral health, meal planning and health action plans.

Recommendations

Staff induction training in all learning disabilities settings should include choking recognition and basic First Aid treatment of choking.

All trainers should increase the emphasis on responding to choking incidents in First Aid training for services that provide care for people with learning disabilities.

In line with the NPSA recommendation, regular practices or drills for staff around responding to a choking incident should be carried out as part of First Aid response training.

The Group recommend the Training Matrix for caregivers of people with a learning disability which may be found at Appendix 8.

Commissioners should work with Speech and Language Therapy services to develop a local course to raise awareness of difficulties with eating and drinking to include dysphagia, the NPSA recommendations and the Mental Capacity Act 2005.

All Primary Care Services in Hampshire are provided with information and web links for the National Patient Safety Agency (NPSA) 'Ensuring safer practice for adults with learning disabilities who have dysphagia' which can be found at - www.nrls.npsa.nhs.uk/resources/?entryid45=59823

All Primary Care Services in Hampshire are sent the NPSA Learning Disability Dysphagia Protocols for GPs (Appendix 6).

The Hampshire Safeguarding Adults Board undertake a communications campaign to raise awareness around the issues of choking.

9 Going into hospital

9.1

Sharing information

Several reports have identified that ensuring that a person's support needs around eating and drinking are clearly identified and communicated to others via a 'health passport' is vital for continuation of care in hospital. (DoH 2008)

In Hampshire, Southern Health Foundation Trust and Solent NHS Trust have produced a document 'Admission to Hospital Information' which may be filled in by the person with a Learning Disability and their carer prior to any admission to hospital. This will ensure that relevant health information may be communicated to the hospital team. There is a small section around 'eating and drinking' however, risk of choking is not specifically mentioned. The Group recommend that this document is reviewed in 2012.

9.2

Health Facilitators

The Health Facilitator role is to support any person with a Learning Disability and ensure that 'diagnostic overshadowing' (where the Learning Disability is viewed as cause of any symptoms) is avoided. Their aim is to improve access to primary and secondary health and acute care for people with a Learning Disability. Support may be around issues of capacity, best interests assessments and in signposting and providing accessible information, setting up services and getting staff to raise any issues.

Referrals to the Health Facilitators can come from anyone, the person with a Learning Disability, community team staff, GP, advocacy services or carers.

The Health Facilitators are also involved with providing workshops and training for ward staff and therapists around the health needs of people with learning disabilities and attend LD Partnership Group where advice publications to people with learning disabilities, carers and staff are approved.

9.3

Health passports and Hospital passports

Health passports are a means of ensuring that a person's verbal and non-verbal communication is understood by others and not simply attributed to their learning disability. For example, screaming or throwing things may be how the person communicates pain or discomfort. Working with someone who the individual knows is key to interpreting their behaviour and avoiding diagnostic overshadowing.





The Learning Disability Services across Hampshire are all using Hospital passports which are carried in to hospital by the individual and describe their particular needs in relation to care to hospital staff. If there is a choking risk, these passports will highlight this. Consent should be given by the individual in relation to sharing of information via these passports.

Recommendations

A 'Hospital passport' is developed for every person with a learning disability to ensure that information around health risks including risk of choking is available to be shared between providers, with the person's consent.

Southern Health and Solent NHS Trust 'Admission to Hospital Information' leaflet is updated in 2012 to include choking risks.

10 Reporting Choking Incidents

The Group recommend that if a choking incident occurs, whether or not there are serious consequences, the incident should be reported and investigated so that steps can be taken to reduce the risk of it happening again.

Choking incidents should be reported to the individual's General Practitioner so that a health assessment can be carried out and appropriate referrals made. In addition, the social worker should be informed in order that the social care assessment of needs can be reviewed in relation to the appropriateness of ongoing placement with the provider.

Incidents where the service user suffers harm must be reported as a safeguarding concern to the Local Authority. In addition, if the incident occurs within an NHS setting, this should also be reported as a Serious Incident requiring investigation and should be reported on the Strategic Executive Information System (STEIS) within two working days of the organisation identifying the Serious Incident.

Any incidents of sudden death, including death by choking, must be reported to the police. A police serious case review will be requested in cases of suspected neglect; for instance, if the person was at known risk of choking and had a care plan in place that was not followed which caused the person to choke.

Death or serious harm of a person in a regulated care setting must be reported to the Care Quality Commission (CQC).

A flow chart can be seen at **Appendix 9** which outlines the incident reporting procedure recommended by the Group.

10.1

The Role of the Police

The police attend sudden deaths, investigate if there are suspicious circumstances and report to the Coroner. In Hampshire, sudden death of an adult would be reported to the Central Referral Unit by the attending officer and will always be referred to the local Public Protection Unit for further investigation. If there is evidence of neglect or corporate manslaughter; for instance where a care plan was not followed, then these will also be referred to a serious case review.

10.2

The Role of the Coroner

The Coroner will seek to find the cause of death but is not looking to apportion blame. The Coroner does have the authority to issue a Rule 43 report under The Coroners (Amendment) Rules 2008. The amended Rule 43 provides that Coroners may produce a report and request a response within 56 days, and may send the report and response to the Lord Chancellor and any other person or organisation with an interest in order to prevent future deaths.

One Rule 43 report issued in 2010 was regarding a choking incident. "To consider a policy review of care plans for patients with learning difficulties in Birmingham and Solihull. Birmingham City Council to include the risk of choking and the need for a carer to remain with a patient throughout a meal; social workers to be advised to attempt the Heimlich method when a patient is choking where possible" (Ministry of Justice 2010).

10.3

The Role of the Health and Safety Executive

The Health and Safety Executive (HSE) have produced guidance around reporting injuries and dangerous occurrences for staff working in health and social care settings. (HSE 2011). This requires that the death of a service user be reported under RIDDOR (Reporting of Injuries, Death and Dangerous Occurrences) when that death is of a service user or patient who may have been affected by someone at work.

Recommendations

All choking incidents involving people with a learning disability must be reported and investigated appropriately.

All choking incidents involving people with a learning disability where death or serious harm occurred are reported to the Police, the Care Quality Commission and the Local Authority (as a safeguarding incident).

A referral to the Health and Safety Executive under RIDDOR arrangements should be considered if choking is due to an employed carer not following the care plan.

II Conclusions

The starting point for this work was the identification and review of five cases in Hampshire where a person with a learning disability had died as a result of choking. After undertaking the work to produce this report, the Group is of the view that premature death through choking is a serious problem for people with a learning disability.

Hampshire County Council serves a population of 1.3 million and had five deaths in five years. On this basis, we might expect a figure of around 50 preventable deaths a year from choking in England. However, during this work it became apparent that there is no national data collection in relation to choking deaths in learning disability clients and no clear understanding of the true national scale of the issue. Although there are pockets of data collection for example, in Bristol, we believe that national data should be collected so that the full extent of this problem can be understood.

Through the work of the Group, we have identified some solutions which may help prevent the early death of a person with a learning disability by choking. Most of these are simple and measures that commissioners and providers of services should already be taking. However, we have been clear that alongside this, we must not remove the right of people with a learning disability to make their own choices about how they live their lives, so we have been mindful of the Mental Capacity Act and how we apply this to support decision making around risk of choking.

The Group have made a number of recommendations with regard to the way forward and this document will be shared with providers across Hampshire and the Isle of Wight.

Finally the Group would recommend that the Safeguarding Adults Boards request that the Department of Health make arrangements to extend the confidential inquiry and collect national data about death by choking in people with a learning disability. This is in order to understand the scale of the problem and seek to address it.





12 Glossary of responsibilities

Agencies have certain responsibilities in commissioning and providing care, some of these are statutory. A glossary of responsibilities suggested by the Group is included at Appendix 10.

13 Summary of Recommendations

Recommendations

- 1 Adults with a learning disability should be supported to take up annual health checks.
- 2 Adults with a learning disability should be supported to attend a dentist for regular check ups.
- 3 Social workers, as part of their annual review of placements, must check that individuals are receiving dental checks.
- 4 All Primary Care Services in Hampshire are provided with information and web links for the National Patient Safety Agency (NPSA) 'Ensuring safer practice for adults with learning disabilities who have dysphagia' which is available online at: www.nrls.npsa.nhs.uk/resources/?entryid45=59823 including the NPSA Learning Disability Dysphagia Protocols for GPs. (Appendix 4)
- 5 Health Commissioners ensure that there is sufficient Speech and Language Therapy resource within the community to respond to requests for assessment of learning disability clients identified as at risk of choking.
- 6 The consent of the person with learning disability must be obtained before any medical investigation or assessment is carried out. This consent – in relation to assessment of eating and drinking – can be gained using the form found at - www.nrls.npsa.nhs.uk/resources/?EntryId45=59823
- 7 All services providing for clients with a learning disability should use an Eating and Drinking Difficulties Screening Tool (Appendix 6), which will indicate whether a choking risk exists and a referral to the GP is needed.
- 8 All services providing for clients with a Learning disability, who have a known risk of choking, should use the documentation found at - www.nrls.npsa.nhs.uk/resources/?EntryId45=59823 in order to ensure the appropriate referrals are made.
- 9 All Services providing for clients with a learning disability should ensure that they follow the instructions provided by the Speech and Language Therapist following an assessment.
- 10 All services providing for clients with a Learning Disability who are at risk of choking as a result of challenging behaviour or deliberate self-harm, should refer the individual to the Learning Disability Health Team for a formal assessment.
- 11 If staff or carers identify that someone is at risk of choking from food or other objects in their mouth, a Mental Capacity Act assessment needs to be considered to support appropriate decision making. For more information, see Section 6 and Appendix 7.

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- 12 If clients, as a result of their behaviours and the consequent risk of choking, are prevented from accessing areas within a residential setting then an application should be considered from the care provider to the Supervising Authority (Local Authority) under the Mental Capacity Act Deprivation of Liberty Safeguards.
- 13 If staff or carers identify that someone is at risk of choking, they must consider a referral to an advocacy organisation for an advocate to support the person with decision making in relation to eating and drinking plans.
- 14 All carers and staff should be involved in the care planning process for people at risk of choking, particularly those who will be implementing the plan.
- 15 Staff should be aware of the consequences of not following an agreed eating and drinking care plan.
- 16 Care plans to support people at high risk of choking should be reviewed at least every 6 months or after any change in the person's health or care.
- 17 Staff induction training in all learning disabilities settings should include choking recognition and First Aid treatment of choking.
- 18 All trainers to increase the emphasis on responding to choking incidents in First Aid training for services that provide care for people with learning disabilities.
- 19 In line with the NPSA recommendation, regular practices or drills for staff around responding to a choking incident should be carried out as part of First Aid response training.
- 20 The Group recommend a standard training matrix which should be used by all those providing care for those with a learning disability and which can be found at Appendix 8.
- 21 The four Hampshire Safeguarding Adults Boards should seek to influence the Department of Health to consider a national data collection about choking deaths in people with a learning disability in order to understand the problem and guide improved practice.
- 22 All Primary Care Services in Hampshire are sent the NPSA Learning Disability Dysphagia Protocols for GPs (Appendix 4).
- 23 The four Hampshire Safeguarding Adults Boards undertake a communications campaign to raise awareness around the issues of choking.
- 24 A 'Health passport' is developed for every person with a learning disability to ensure that information around health risks including risk of choking is available to be shared between providers, with the person's consent.
- 25 All choking incidents involving people with a learning disability should be reported and investigated appropriately as described in section 10 and appendix 9.

Appendix

I

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Appendix 2

Acknowledgements

Members of the Multi-Agency Group and other people involved in this review

Lucy Butler;	Assistant Director Adult Services Hampshire County Council
Jane Duncan;	Head of Safeguarding and Care Governance Hampshire County Council
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Appendix 3

Media Items

Choking deaths

April 2010

A disabled woman died after choking on a piece of pancake, an inquest heard. L, 47, who lived at a care home, took the food from the kitchen after dinner. The inquest heard that L, who had autistic traits and suffered from anxiety, tried to hide the food from staff as she knew she was not supposed to take it but ended up choking. A care worker stated: "We had just finished our evening meal which was pancakes. L wanted more but we said there wasn't any more. She was asked to take her cup back to the kitchen, wash her hands and clean her teeth. I then collected the other plates and as I walked to the kitchen she came out and was chewing. I asked what she had and realised it was pancake."

(Anonymous 2011)

A CARE home resident with severe learning difficulties and eating problems died accidentally after choking on biscuits. M, 39, had the mental age of a three-year-old, suffered from autism and had an "obsession" with food, an inquest into his death was told. Staff at the residential home where he had lived for several years, took considerable precautions to prevent him from getting hold of food, including locking the kitchen and even cutting down apple trees in the garden. M who was on a carefully controlled and gluten free diet, had found some biscuits in the room of another resident. The food had been kept out of sight in a wardrobe. A carer said M had been left alone for five to 10 minutes while she and a colleague were working in the kitchen. M managed to get hold of the biscuits and quickly started to eat them. His mouth was full of broken-up biscuit and he was struggling to breathe and was pacing around. Despite the best efforts of the carers and a member of the public called in from a nearby house, M continued to choke and collapsed.

Dr D recorded that M had died as the result of a tragic accident and asked for a transcript of the hearing to be sent to the Adult Safeguarding Board. He said that in future, risk assessments should not just extend to individuals in care homes, but to others living with them. He added: "Without in any way implying liability, it would be helpful to emphasise the fact that the one learning point here is the need to conduct the risk assessment of not just the client, but of other clients with specific needs."

(Furniss, E. 2010)

Reducing the risk of choking for people with a learning disability

Feb 2011.

A resident at a specialist care home choked to death on his breakfast of toast and peanut butter; an inquest was told. Staff at the care home battled in vain to save B, a Down's syndrome resident who suffered from obsessive compulsive disorder. The coroner recorded a verdict of accidental death on B who was 44 and had lived at the home for more than five years. The home manager said he had spotted B coughing while eating his food. He told him he was 'all right' and carried on coughing and talking, which was something he did from time to time. He said the incident did not set any 'alarm bells' ringing. When matters worsened he gave him a few slaps on the back 'which normally did the trick.' B was then given a drink 'to wash away' the cause of the problem in his throat. As concerns rose an ambulance was called for and the manager gave B the Heimlich Manoeuvre which is designed to cause the patient to expel any blockage in the airway. The method was repeated, but without success. Paramedics then arrived, using a special pump which broke because the blockage of food could not be moved. A paramedic said the food in his throat was half-eaten. In the end the obstacle was removed by hand and the airway was cleared as CPR treatment continued, but to no avail. B died at the scene. A post mortem examination confirmed that he died by choking on his food.

(Anonymous 2011)

STAFF at a care home were praised for their attempts to save a patient who died choking on food. D, 48, had various mental health issues, including bi-polar disorder and learning difficulties. One of her symptoms was an obsessiveness over food. On the morning of her death she had managed to get into the kitchen of the home and had tried to stuff too much food into her mouth at one time. The kitchen was being used to store leftover party food from a resident's 21st birthday the day before. In a statement read out at the inquest, a nursing assistant said: "I was walking down the corridor pushing a resident in his wheelchair. I noticed the kitchen was unlocked and said I would lock it before D woke up, but she was already in there. D was taken to hospital where she later died of asphyxiation.

Recording a verdict of accidental death, the coroner said: "Despite the door being left unlocked by the staff, they did make very substantial efforts to try to help D and for that they should be commended. "The health trust took this matter very seriously and had an independent inquiry." A report that resulted from this inquiry recommended making the protocols for keeping kitchen doors locked more clear and also said other centres could learn from the tragedy.

(Anonymous 2010)



April 2011

A choking incident occurred in a nursing home in Hampshire. A 66 year-old man, D, known to be at risk of choking due to a tendency to cram food into his mouth and eat too quickly choked after taking another resident's bread pudding at a mealtime. The carer present gave D a glass of milk to wash away the food, however milk started coming out of his nose and mouth. Staff attempted back slaps whilst D was slumped in a chair also abdominal thrusts. CPR and suction was attempted and D was transferred to hospital. All staff had received basic life support training and residents were supervised at mealtimes. The home was investigated under safeguarding procedures and a series of measures to reduce the risk of such an event happening again have been instigated. These include seating service users on soft/puree diet away from those on normal diet, and informing relatives of dietary restrictions.

(From case notes 2011)

Learning disabilities dysphagia protocol for General Practitioners

Prevalence and associated health risk

Feeding, swallowing and nutritional problems have a high prevalence among people with learning disabilities. They can have serious repercussions including poor nutritional status, dehydration, aspiration and asphyxiation. They can be life threatening or lead to life threatening problems. Adults with cerebral palsy and those with severe intellectual and physical disabilities have a high incidence of dysphagia and patients with spastic quadriplegia are at particular risk of aspiration. Although there is limited research into people with learning disabilities who have dysphagia, there is evidence that successful management decreases risk.

History and potential symptoms that could indicate dysphagia

Does your patient exhibit any of the following:

- ☐ History of choking episodes
- ☐ Coughing during and/or after meals
- ☐ History of frequent chest infections
- ☐ Increased shortness of breath when eating or drinking
- ☐ Dysarthria
- ☐ 'Bubbly' voice quality
- ☐ Failure to maintain weight
- ☐ Slow eating and/or refusing food
- ☐ Regurgitation
- ☐ Risk factors
- ☐ Cerebral palsy
- ☐ Severe and complex disabilities
- ☐ Previous history of CVA
- ☐ History of dementia

Suggested actions

In all cases:

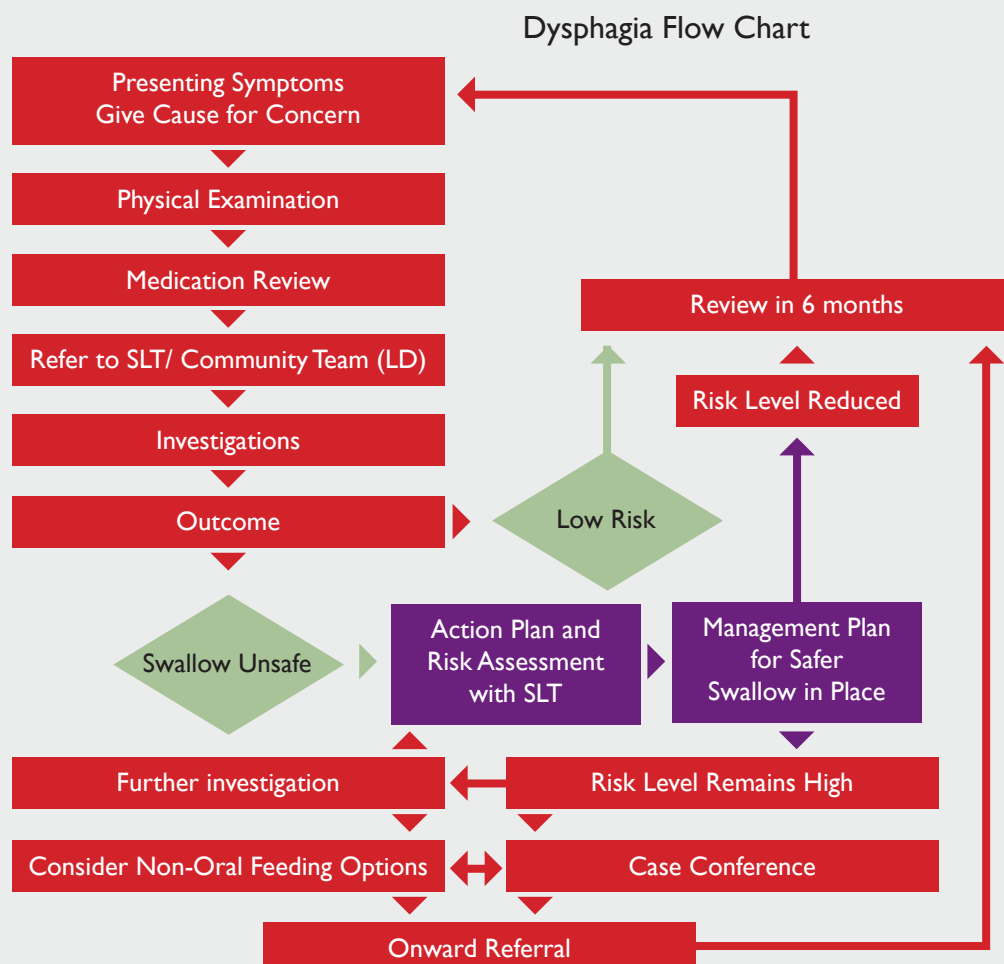
- request a speech and language therapy dysphagia assessment
- conduct a simple physical examination of oropharyngeal cavity
- review medication for drugs with sedative or cholinergic side effects
- look for evidence of weight loss and malnutrition
- consider haematological/ biochemical/ radiological assessment including
- videofluoroscopy (this may be requested by the speech and language therapist)

A Multi-agency review in Hampshire

- always consider co-existent or other pathologies
- consider other causes including oesophageal stricture with or without regurgitation
- consider referral to colleagues in learning disability services including a dietician for advice about diet and food consistency
- consider advice from a physiotherapist.

Good practice

- assess efficacy of swallow as part of any health check for people with learning disabilities
- consider consent issues. See the Mencap website for guidance at www.mencap.org.uk
- take into account the individual's level of comprehension and communications ability and tailor their management needs accordingly
- consider quality of life issues on a multi-disciplinary basis and involve family members and carers when making decisions about care management
- continually review the condition because it is likely to deteriorate with age
- see NICE guidelines on management of dysphagia at - www.nice.org.uk.



Appendix 5

Letter to Colleagues



South of England

South Central Strategic Health Authority

To:
DoN
Safeguarding Leads LA/PCT
LD Providers
LD Commissioners LA/PCT
PCT Directors of Commissioning
29th February, 2012

First Floor, Rivergate House
Newbury Business Park
London Road
Newbury
Berkshire
RG14 2PZ
01635 275500
www.southcentral.nhs.uk

Dear Colleagues,

Safety alert - Difficulty in swallowing ('dysphagia') is a serious problem for some adults with learning disabilities and, in serious instances, has led to death.

Dysphagia is a serious problem for some adults with learning disabilities and, in serious instances, has led to death.

Through incident reporting and safeguarding we have become aware of a number of deaths involving people with learning disability choking. This letter is to raise awareness of this serious issue, and share national good practice.

There has been little work done in this area, as you are probably aware the National Patient Safety Agency (NPSA) undertook some work in 2007, they received 605 reports of choking-related incidents involving adults with learning disabilities between 30 April 2004 and 30 April 2007.

The majority of these incidents (58 per cent) took place at mealtimes. Incidents occurring in residential care homes accounted for 41 per cent of incidents and 58 per cent took place within inpatient and assessment services. The remainder occurred in public places. NPSA produced guidance called 'Ensuring safer practice for adults with learning disabilities who have dysphagia'.

Resources for healthcare staff, July 2007 (see attached) the document outlines the issues facing adults with learning disabilities who have dysphagia and introduces support materials that can provide practical help for these people. The tools can be adapted for local use and for any adult who has dysphagia.

A Multi-agency review in Hampshire


Hampshire Adult Safeguarding Board set up a multi-agency group who have been undertaking a review of a number of choking cases and will be making recommendations for care of all service users/patients at risk of choking. This will include those people who had a diagnosis of dysphagia (swallowing difficulties) and those where illness or behaviour placed them at risk of choking. We will share this work once completed.

We would ask you to review your current policies and procedures to ensure they include a policy on dysphagia care for adults with learning disabilities. The policy should ensure that:

- All adults with dysphagia have an individual management plan that is regularly monitored and updated.
- All adults with dysphagia are assessed so as to accurately determine the level of dysphagia they have and the associated risks.
- Ideally this assessment should be carried out by specialist practitioners, often speech and language therapists and those trained to recognise the varying symptoms of dysphagia in adult clients with communication difficulties.
- The consent of the person with a learning disability must be obtained before any medical investigation or assessment is carried out.
- If staff or carers identify that someone is at risk of choking from food or other objects in their mouth, a mental capacity assessment needs to be considered to support appropriate decision making.
- All choking incidents involving people with a learning disability should be reported via the Serious Incident procedure / safeguarding and investigated appropriately.

Please find a good practice checklist attached for your internal use. We will run a half day workshop later this year to launch the Hampshire Adult Safeguarding Board work and to share best practice.

Yours Sincerely



Jan Fowler



Julie Kerry

Cc; Caroline Ainslie
Caroline Heason
Jill Pellett
Gill Duncan
Jane Duncan

Appendix 6

Eating and Drinking Difficulties

Screening Tool

Tick if present

- ☐ Does the person cough when eating and/or drinking?
- ☐ Has there been a choking incident in the last year?
- ☐ Has the person had pneumonia or recurrent chest infections in the last 12 months?
- ☐ Is there any evidence of malnutrition?
(weight loss, skin breakdown, severe fatigue, hair loss – circle all that apply)
- ☐ Or dehydration?
(urine infections, strong urine, constipation, thin dry skin – circle all that apply)
- ☐ Does the person have a condition that might indicate dysphagia?
(Cerebral Palsy, Down's Syndrome, dementia, other deteriorating condition – circle all that apply)

If you have ticked any of the above sections, please discuss with the Learning Disability Health Team or the person's GP.
A referral for a swallowing assessment may be necessary with the Speech and Language Therapist

Name of person filling out form:

Name of person information gathered from:

Date form filled out:

Appendix 7

Mental Capacity Act assessment for people with learning disability at risk of choking

Assessment: You need to assess whether the person can make their own decision, in this case:

Can the person decide what to put in their mouth?

In order to decide whether the person can make that decision, whether they have mental capacity to make that decision, you need to consider the following issues:

- You should start by assuming that they can make their own decision, provide all support possible for them to make their own decision and remember that what others might view as an 'unwise' decision does not on its own indicate a lack of capacity.
- Then consider whether the person has an 'impairment or disturbance of the mind or brain' e.g. learning disability, dementia, serious mental health problem.
- Then consider, have you given the person all the reasonable assistance they need, including information and the appropriate conditions to use that information, to be able to make this decision for themselves?

If yes,

- a With all possible help given is the person able to understand that they need to make decisions about whether or not to put certain consistencies of food, or other objects into their mouth?
 - b Are they able to retain the information long enough to make this frequently occurring decision?
 - c Are they able to weigh the information and understand the consequences i.e. that there is a risk of them choking if they put the food/object in their mouth?
 - d Are they able to communicate the decision, with all possible help given?
- If the answer to all these questions a – d is yes, then the person has the capacity to make the decision themselves and you cannot make it for them. Any Support Plan developed to manage this identified risk will need to be done so with the person's involvement and consent.
 - If the answer to any of these questions a – d is no, then the person is not judged to have capacity and someone will need to make the decision for them. If this decision involves supporting the person with what they eat/put in their mouth, then a Support Plan will need to be developed and implemented in their best interests.
 - It is important to record this assessment, either in case notes or in a more formal way – refer to your own agency for guidance on this – so that you can demonstrate compliance with the Mental Capacity

Reducing the risk of choking for people with a learning disability

Act. The CQC website contains guidance on the Act: -

http://www.cqc.org.uk/_db/_documents/RP_PoCIB2B_I00563_20100825_v3_00_Guidance_for_providers_MCA_FOR_EXTERNAL_PUBLICATION.pdf

Hampshire County Council also has an MCA toolkit that anyone can use for recording more complex decisions, and it can be found at:

www.hants.gov.uk/mental-capacity-toolkit0408-5.pdf

Best Interests Decision: If the person does lack capacity to make this decision themselves, then someone else will have to make the decision on their behalf – usually either a relative, care worker, social worker or doctor – and the outcome of the decision must be in their best interests and the least restrictive possible option. In this case, it could well be an employee of a residential or nursing home who is best placed to make the decision, having consulted all relevant family members and professionals. It will most likely be the person responsible for developing and implementing the Support Plan needed to carry out the best interests decision which is reached, such as the registered manager or key worker, depending upon local arrangements.

Follow this checklist to see who else you should involve in the process of reaching your decision:

- Anyone named by the person lacking capacity as someone to be consulted
- Anyone engaged in caring for the person or interested in their welfare
- Any attorney appointed under an Enduring/ Lasting Power of Attorney
- Any deputy appointed by the Court of Protection
- Independent Mental Capacity Advocate (IMCA), if involved.

The decision you reach may well be something like this:

- The person's food should be either naturally soft e.g. scrambled egg, mashed potato, yoghurt, or should be pureed, and cannot contain any lumps. This is in their best interests as it will minimise the risk of choking, but retains some elements of whole food for increased enjoyment and variety.
- The person's food must always be fully pureed, this is in their best interests as their risk of choking is so high.
- As far as is possible the person should not have unsupervised access to items which could be put in their mouth and cause a choking hazard.

Once again it is important to record this decision appropriately, and the additional consultation and assessments that took place in the course of making the decision – the HCC toolkit above has space to record the decision.

If the decision will require some support or care to be offered to implement it, then you should ensure that there is a clear Support Plan developed to implement this decision, agreed by a suitably qualified professional.

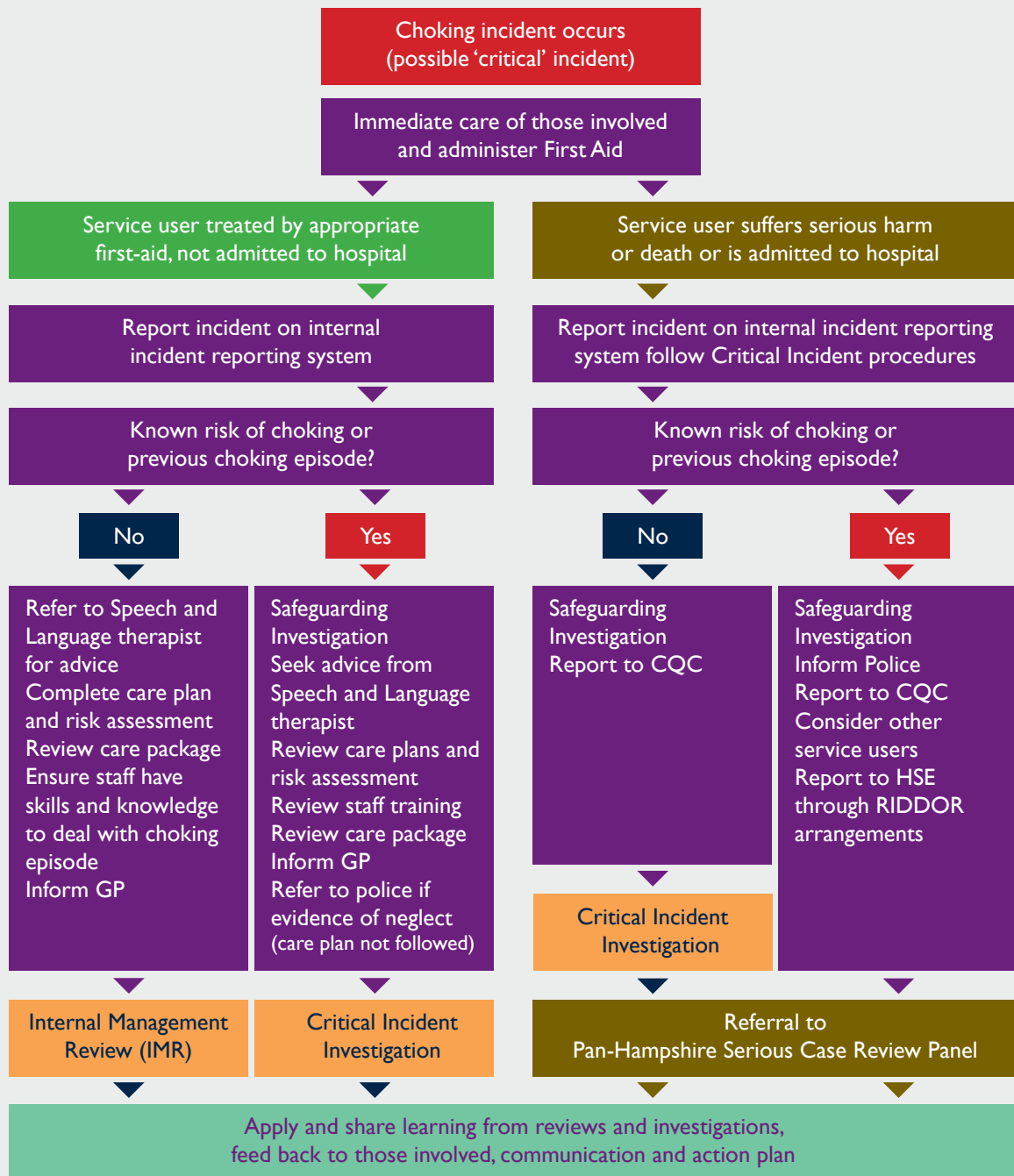
Appendix 8

Training Matrix for staff and others caring for persons who may be at risk of choking

Persons Involved	Level of Intervention	Recommendations
General Public	General Awareness	Leaflets, Posters, Website information Signpost to NPSA information
Health and Social Care staff who have regular contact with service users but with no known risk of choking	General Awareness Emergency First Aid Training	As above <i>Plus</i> Emergency Aid training that includes signs and symptoms of choking and the First Aid response. The dysphagia screening tool from the NPSA guidance
Health and Social Care staff who have regular contact with service users who have an identified problem with eating and drinking – (including behavioural) or a diagnosis of Dysphagia.	Emergency First Aid Training Eating and Drinking Awareness training Course Challenging behaviour training –(i.e. risk may be due to eating too quickly or eating inedible objects) Awareness of screening tool Access to health care professionals for individualised response and assessment Development and Implementation of a clear individualised risk assessment and management plan Mental Capacity Act training	As above Eating and Drinking Awareness training Outcomes: <ul style="list-style-type: none"> ● Explore the understanding and perception of nutrition and swallow skills. ● To identify the physical, emotional and environmental needs of people with Learning Disabilities in relation to eating and drinking. ● To develop our understanding of the stages of a normal swallow. ● To develop our skills in making mealtimes as safe and pleasurable as possible: ● modifying food, drink and the environment ● communication at mealtimes ● good practice in feeding and support techniques ● menu planning. ● Identify support services and referral process. Risk assessment and management plans to be drawn up in consultation with health care professionals including positive behavioural support plans, based upon a functional analysis where the risk issue is related to behaviour
Health professionals (including nurses)	Training in: Dysphagia Emergency First Aid	GPs and health care staff to adhere to NPSA guidance.

Appendix 9

Flow chart for reporting of choking incidents



Hampshire Safeguarding Adults Board Multi-agency Group 2011

Appendix 10

Glossary of responsibilities

Agency	Assurance Mechanism	Detail
SHA/PCT	Safeguarding	Protect vulnerable people from abuse and neglect
	LD Partnership Boards	Learning Disability Health Self-Assessment which is being implemented nationally as part of Valuing People Now 2009 (DoH) to help PCTs have a better understanding of the needs and experiences and services provided. The four top targets are: <ul style="list-style-type: none"> • Campus Closure and resettlement • Reducing health inequalities • Ensuring NHS services are safe • Implementation of Valuing People Now
	Serious Incident Management	NHS organisations report serious incidents to SHAs/PCT's via a national reporting system in order to both identify learning opportunities for improving patient safety and to ensure NHS trusts and PCTs have robust arrangements in place to investigate incidents and prevent recurrence.
Local Authority	Incident investigation	SHAs have a statutory responsibility to commission independent investigations into particular types of incidents or clusters of incidents
	Safeguarding Lead	Protect vulnerable people from abuse and neglect. Service managers for Commissioning or Care Management (or equivalent) will retain lead coordination responsibility for the safeguarding / abuse investigation but may delegate authority to team managers
	Training	Developing and training the social care workforce
	Adult Safeguarding Board	Review and evaluate Safeguarding practice, produce annual business plan
	Incident reporting	LA must inform the Care Quality Commission where the alleged abuse involves a registered provider.
Police	Incident investigation	Investigate sudden deaths where abuse or neglect may be a causative factor and intervene with perpetrators (such as in a case of neglect where staff have failed to provide agreed care)
	Act as Coroner's Officer	Will attend a sudden or unexpected death such as a death due to choking and report to the Coroner
	Secure evidence	Gather evidence where a crime is suspected
Coroner	Identify cause of death	Establish facts and report cause of death
	Report concerns	Report and escalate any concerns to the provider or as Rule 43 concern

Reducing the risk of choking for people with a learning disability

Provider service managers	Identify service users at risk from choking	Providers should assess the care required by service users and refer to specialist support if risk assessment indicates. SaLT referrals and Dietician referrals may be instigated by providers
	Staff training and ongoing support	Providers have a responsibility to ensure that staff caring for vulnerable service users are trained to provide the care required. This includes basic First Aid and specific training relating to risks identified in the individual's risk assessment.
	Inform other agencies about adults at risk	Inform the service user's GP, Social Worker/Care Manager and representative if a service user becomes at risk of choking
	Report incidents where a service user suffers harm	Report choking incidents appropriately to: CQC, GP, Social Worker, Police, Safeguarding, Health and Safety Executive.
	Safeguarding	Must report safeguarding concerns to Local Authority and appropriate bodies. This will include incidents where service users suffer harm as a result of choking.
Care workers in provider & support services	Adhere to code of conduct	Follow care plans, health professionals' and managers' advice, attend training provided, report issues, seek assistance when unsure.
Speech and Language Therapist	RCSLT Best Practice Guidance	Consider referrals, undertake assessments and produce management plans for people with a learning disability at risk of choking due to dysphagia.
General Practitioner	Directed Enhanced Service (DES)	Complete an annual health check on all patients with a diagnosed learning disability
Dental practitioners	BSDH Oral Health Guidelines	Provide regular oral health checks for people with a learning disability
CQC	Registration Standards	CQC register and therefore license providers of care services to ensure that they meet essential standards of quality and safety and monitor them to make sure they continue to meet these standards
DoH	NHS Operating Framework	Improving care and outcomes for people with learning disabilities.
	Six Lives	The Parliamentary Ombudsmen investigated complaints that were made by Mencap on behalf of the families of six people with learning disabilities, all of whom died between 2003 and 2005 while in NHS or local authority care. The investigation reports illustrate some significant and distressing failures in service across both health and social care, leading to situations in which people with learning disabilities experienced prolonged suffering and inappropriate care. The NHS has been required to make regular progress reports.
Social Workers	NHS and Community Care Act 1990	Ensure that the placement or service meets the assessed needs of the person with learning disability

The work was carried out by Hampshire Safeguarding Adults Board
on behalf of the following partners;
Hampshire County Council
Portsmouth City Council
Southampton City Council
Isle of Wight Council
Hampshire Constabulary
Southern Health NHS Foundation Trust
Solent NHS Partnership Trust

Produced by Hampshire County Council Adult Services Department
Photos credited to Fotolia, NHS, Charlotte Morse
Printed by Hampshire Printing Services
September 2012

