The Patients Association

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speaking up for change

# Survey of medicines related care of residents with dysphagia in care homes

**OCTOBER 2015**

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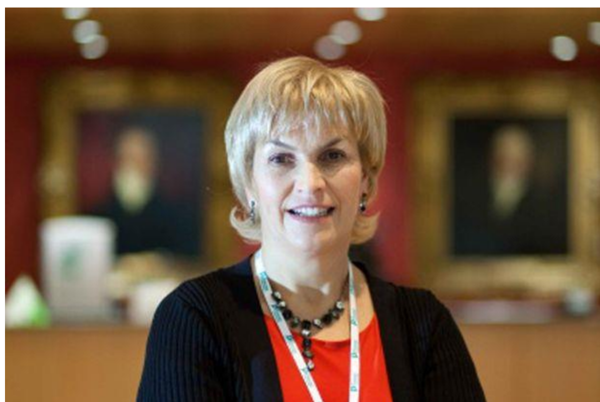
## Foreword



The NHS was set up to provide health care from the cradle to the grave. Yet from our National Helpline we hear very worrying trends regarding the care of older people, care of the dying and those who are struggling to access appropriate care and treatment.

This report is a qualitative study arising from a survey looking at the medicines related care of residents with swallowing difficulties in a small sample of 30 care homes. The survey found that residents affected by swallowing difficulties was a significant issue with as many as 50% of the residents in a care home being affected in this way. The potential for developing dysphagia (or swallowing difficulties) becomes increasingly common as people grow older[1] with previous studies suggesting the incidence of dysphagia amongst older people in care homes could be as high as 68%.[2]

The study has produced anecdotal evidence that the arrangement of having a preferred GP to a care home has led to improved medication review and prescription arrangements based on GPs having a better understanding of the care needs of residents. However it also produced evidence that, despite liquid forms of medication being a preferable option for many people with swallowing difficulties, budget concerns were putting GPs off from prescribing medication in this form.

Amongst other problems, people with swallowing difficulties often struggle to take medication in the form of tablets. This can lead them to trying to chew the tablets so that they become easier to swallow or attempting to swallow tablets causing them to choke or have coughing fits.

Care homes will take a number of actions to try and help residents to overcome their swallowing difficulties and continue to take their medication. In some instances this will lead to medication being crushed, melted and dispersed and then mixed with soft or liquidised forms of food to assist with its consumption.

However this is not a straightforward issue. Altering medication in these ways affects the normal arrangements for the body's absorption of medication increasing the chances of side effects or reducing the drugs' effectiveness. It can also lead to circumstances whereby someone is being covertly treated with medication and is unaware of this.

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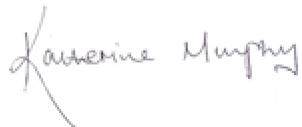
[1] Leder, S. B. and Suiter, D. M. (2009) An Epidemiologic Study on Aging and Dysphagia in the Acute Care Hospitalized Population: 2000-2007. Gerontology, 55, 714-718

[2] Rosenvinge, S. K. and Starke, I. D. (2005) Improving Care for Patients with Dysphagia: Age Ageing (2005) 34(6): 587-593

There was evidence of good practice being adopted in some of the care homes surveyed but this also highlighted the need to raise the profile of people with swallowing difficulties through better training for staff and provide more effective care to the substantial numbers of people in care homes who are affected in this way.

This report includes a series of recommendations directed at care homes, Clinical Commissioning Groups and the Care Quality Commission to support improved care practice and we hope that these will be adopted by the respective organisations. When determining medication arrangements for people with dysphagia in care homes it is recommended that the best form of treatment for the individual service user should be the primary consideration rather than decisions based on cost.



**Katherine Murphy**
**Chief Executive**

## Executive Summary

Medicines are the principal therapeutic tool used by the NHS which spent 15 billion pounds on medicines in England in 2013 (Health and Social Care Information Centre 2014). Used as intended, medicines have the capacity to sustain and maximise people's independence and personal dignity. However, medicines are also the most frequent cause of error that results in harm to service users.

The potential for developing dysphagia (or swallowing difficulties) becomes increasingly common as people grow older.[3] With previous studies suggesting the incidence of dysphagia amongst older people in care homes could be as high as 68%.[4]

This report is a qualitative study looking at the medicines related care of people with dysphagia (or swallowing difficulties) living in care homes. The study was conducted because of concerns to our national helpline from relatives and evidence of the increasing incidence of dysphagia amongst older people in care homes and was based on a survey of 30 care homes.[5]

The numbers of service users accommodated in the different care homes surveyed varied between 20 and 90 residents and the proportion of people affected by some form of swallowing difficulties varied. The highest incidence was a home reporting that over 50% of their residents were affected in this way.

Respondents to the survey suggested that concerns surrounding the cost of liquid medication was a factor in prescription arrangements for residents with dysphagia despite evidence that liquid forms of medication are a preferable option for people with swallowing difficulties.[6]

Crushing, melting or dispersing tablets alters the normal arrangements for the body's absorption of medication with attendant risks associated with increasing the likelihood of side effects or reduced effectiveness.[7] This is compounded when considering that one of the most common types of medication administration error is incorrect crushing of tablets.[8] However in over two thirds of the homes crushing, melting or dispersing tablets had become a daily necessity to assist people with swallowing difficulties to take their medication. The prescription of liquid forms of medication offers a useful way to address this concern. Despite this, not all medication is available in this form. This study found evidence of limited awareness of the impact of tampering with medication reinforcing the importance of training in this area for care staff.

An arrangement of having a preferred GP provider to a care home has previously been highlighted as being of benefit in improving the use of medicines in care homes and there was anecdotal evidence

[3] Leder, S. B. and Suiter, D. M. (2009) An Epidemiologic Study on Aging and Dysphagia in the Acute Care Hospitalized Population: 2000-2007. Gerontology, 55, 714-718

[4] Rosenvinge, S. K. and Starke, I. D. (2005) Improving Care for Patients with Dysphagia: Age Ageing (2005) 34(6): 587-593

[5] Leder, Suiter (2009) An Epidemiologic Study on Aging and Dysphagia

[6] Wright D, Chapman N, Foundling-Meah M, Greenwall R, Griffith R, Guyon A, Merriham H (2015) Guideline on medication management of adults with swallowing difficulties

[7] Royal Pharmaceutical Society (2011) Pharmaceutical Issues when Crushing, Opening or Splitting Oral Dosage Forms

[8] Wright D et al (2015) Guideline on the medication management of adults with swallowing difficulties

from this study of improved medication review and prescription arrangements arising from such a provision.[9]

In over 70% of the homes medication was being mixed with food to make it easier to administer. This raised important concerns about ensuring that service users remain aware that medication is being administered in this way, together with the possibility of reduced or missed doses of medication, if the affected service user does not consume the full portion of food.

The majority of homes reported some awareness of the circumstances under which it would be legal to covertly administer medication to residents (for example where it was disguised in food). However the study highlighted the need for all care homes to ensure adequate safeguards for residents, provide training and guidance to staff in this important area and ensure that care home residents have received a mental capacity assessment with subsequent access to an advocate to represent their best interests in deciding whether covert administration of medication is justified.

Despite the numbers of people affected by swallowing difficulties in care homes only 10% of the homes surveyed had a specific protocol to guide staff in administering medication to people with dysphagia and only 20% had arranged training in this important area.

The report includes a series of recommendations directed at care homes, Clinical Commissioning Groups and the Care Quality Commission to improve practice in relation to the medicines related care of people with swallowing difficulties living in care homes.

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[9] Alldred D P, Barber N D, Buckle P, Carpenter J, Dickinson R, Franklin B D, Garfield S, Jesson B, Lim R, Raynor D K, Savage I, Standage C, Wadsworth P, Woloshynowych M and Zermansky A G (2009) Care home use of medicines study (CHUMS): Medication errors in nursing & residential care homes - prevalence, consequences, causes and solutions, London: Report to the Patient Safety Research Portfolio, Department of Health

## 1. Introduction

1.1 Medicines are the principal therapeutic tool used by the NHS which spent 15 billion pounds on medicines in England in 2013 (Health and Social Care Information Centre 2014). Used as intended, medicines have the capacity to sustain and maximise people's independence and personal dignity. However, medicines are also the most frequent cause of error that results in harm to service users. As highlighted by Barber et al (2009), in research looking at medication errors in care homes for older people, care home residents are a vulnerable population who are at particular risk from medication errors. The authors' noted that of the residents in care homes surveyed for their report two thirds were exposed to one or more errors. A recent report by The Centre for Policy on Ageing (2011) estimated that a care home resident being administered medication three times a day would be 84% likely to receive at least one medication administration error a week. To provide protection to service users, five distinct areas of law come together to ensure that medicines are prescribed, dispensed and administered to service users safely.

1.2 The law regulates the right to prescribe and administer medicines through the provisions of the Human Medicines Regulations 2012. The standard of prescribing and administration is underpinned by the care worker's duty of care to the service user, duty of care to their employer and professional code of standards and ethics. Care workers who fail to discharge their duties to the service users in their care in relation to medicines management and administration can face prosecution, dismissal and sanction by their professional regulator.

1.3 Care providers must also discharge their duties to the service users in their care. In relation to medicines management, care providers must ensure safe care and treatment of service users under the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014. Care providers are vicariously liable for the negligent acts of their staff and could be required to pay compensation to service users harmed by medication error. A recent change in the law has led to the Criminal Justice and Courts Act 2015 applying to individual care workers stipulating that "it is an offence for an individual who has care of another individual by virtue of being a care worker to ill-treat or wilfully to neglect that individual". In this context poor medicines management such as unsafe crushing of solid form medicines, unlawful use of covert medicines and failure to administer medicines as prescribed are potential sources of claim and prosecution.

1.4 To protect service users from harm and minimise their liability it is essential that care providers are able to show that they have discharged their legal obligations by ensuring they have in place effective practices together with policies and procedures that promote safe and lawful medicines management and that their staff are properly trained to administer medicines lawfully and safely.

1.5 This report arises from a qualitative study of the medication practices in a limited sample of care homes, in particular relating to the care of people with dysphagia (or swallowing difficulties). The potential for developing dysphagia becomes increasingly common as people

grow older (Leder and Suiter 2009) and studies have suggested the incidence of dysphagia amongst older people in care homes being as high as 68% (Rosenvinge and Starke 2005).

## 2. Size and design of the survey

2.1 The survey covered a total of 30 care homes with a total of 102 people reported to be affected by significant swallowing difficulties. One of the home managers spoken to said that as many as 1 in 3 of her service users (or 25 people) had some form of difficulty swallowing but four were particularly affected. Another manager reported that over 50% of the service users in the home had swallowing difficulties with two people using percutaneous endoscopic gastronomy (PEG) feeding tubes. The number of service users accommodated in the different care homes covered varied between 20 and 90 service users. The survey was conducted by telephone interview with the registered manager (or a person nominated by the registered manager). Care homes which did not have a manager registered with the regulator were excluded from the study. The survey questionnaire was initially tested with a sample of five homes before being extended to the larger sample. A series of standard questions were put to the managers of the homes and the questionnaire with details of the questions applied is attached as Appendix 1 to this report.

## 3. Survey findings

- **Crushing, melting/dispersing or splitting medication**

3.1 The Centre for Policy on Ageing (2011) has reported that one of the most common types of medication administration error is incorrect crushing of tablets. All tablets and capsules are designed to release the active drug into the body from a certain location which is usually the stomach or small intestines at a certain rate. Crushing or dispersing tablets alters this and in most cases will increase both the amount and absorption of the drug. This becomes a real problem when a medicine has to be kept within a narrow concentration range in the blood, when the tablet or capsule has been designed to release a large dose over an extended period of time or when a tablet or capsule ingredients have a coating which is designed to protect the drug, protect the stomach from the drug or release the drug after the stomach. In all cases crushing or dispersing the medicine can either increase the likelihood of dose related side effects or reduce the effectiveness of the drug (Wright et al 2015).

3.2 Accordingly it is important that full consideration is given when it is proposed that medication is interfered with in this way on account of an individual's particular difficulties in taking medication in its prescribed form.

3.3 Amongst the care homes surveyed there was a variety of responses to the practice of crushing, melting, dispersing or splitting medication. In twenty-two of the care homes surveyed crushing, melting or dispersing and splitting of medication was happening daily, five said that they were not undertaking any of these practices because they had no service users who were so significantly affected by swallowing difficulties that it proved necessary but confirmed there were occasions when this was a daily practice due to the needs of the service users in the home. One of the managers said that it was her practice to never split tablets, another said that she would only split tablets if they were scored. One manager reported that when

splitting tablets was required, this was undertaken by her supplying pharmacy and the medication was supplied pre-split in the monitored dosage system supplied to the home.

3.4 Three of the care homes commented that not all medication was available in a liquid form and that on occasion this required the home to crush, melt or disperse medication. However, in most therapeutic categories there is a liquid medicine available. These homes reported that their GP was supportive of the approach of prescribing liquid medication to service users with swallowing difficulties.

3.5 Over two thirds of the homes reported that their GPs were concerned about the cost of liquid medication and this was a factor in whether they were prescribed for service users/patients. For example one manager said that her GP saw liquid medication as a 'last resort' due to budgetary concerns. Another home reported that their GP actively recommended other forms of approach to the administration of medication for people with swallowing difficulties and would only prescribe liquid medication if care staff actively advocated for this due to the particular needs of the service users' affected.

3.6 Such medicines are unlicensed medicines and may take the form of 'specials' (made under a specials licence by a manufacturer), an imported product, an extemporaneous product (made by a pharmacist combining ingredients) or manipulated products in which the formulation is altered by for example crushing tablets.

It is recommended that Specials and licensed imports should be considered first, followed by extemporaneous medicines, and then manipulation. (Tomlin S et al, 2009, Making medicines safer for children)

Not all Specials are made the same way. These range from some manufacturers using batch manufacture making them under the same quality standards as licensed products and the products undergo finished product testing; to the other extreme where tablets are crushed and suspended where little or no testing is done. (Royal Pharmaceutical Society, Professional Guidance for the Procurement and Supply of Specials 2015).

When products are used outside their licence (e.g. crushing non-crushable tablets) a greater liability rests with the individual prescriber, dispenser and/or person responsible for the provision or administration of the medication.

3.7 As noted in paragraph 3.1 of this report crushing, melting or dispersing medication can have an impact on the efficacy of different forms of medication. As a result it is important that these steps are taken only after careful consideration of the particular needs of a resident who is having difficulty taking medication in a conventional manner. Over two thirds of the care homes surveyed stated that crushing, melting, dispersing or splitting medication was an activity taking place daily.

- **Gaining authorisation from a doctor if care home has to crush /melt or disperse tablets**

3.8 All care homes reported that they would get authorisation from a doctor before crushing, melting or dispersing tablets. All homes, except for one, reported that the GP was 'happy' to give such authorisation with concerns relating to the cost of liquid medication affecting the decision. When questioned on this area a number of homes advised that they asked the GP to put this confirmation in writing for example by signing the resident's case record to confirm that had have given their authority for the medication to be altered prior to administration.

One home reported that their GP was reluctant to give authority and put this in writing in respect of the crushing, melting, dispersal or splitting of medication. They noted that they did not need to crush, melt/disperse or split tablets at the time the survey was being conducted but highlighted that this could present difficulties for them in the future.

3.9 Five homes advised that it had now become their established practice to record advice received from the GP in the individual service user's care plan and the GP was asked to sign the record. Where the advice was given over the phone this was recorded on the record and the GP was asked to sign the record during their next visit to the home. This was seen as an important safeguard for both the home and the GP in documenting the decision.

3.10 It is expected good practice that care homes should seek authorisation from their GP prior to altering medication by crushing, melting or dispersing medication and should seek advice from a pharmacist prior to taking such steps to confirm that this will not affect the basic efficacy of the drugs involved. In such circumstances liquid forms of medication may often offer a better option than altering the form of the medication prescribed.

- **Seeking advice from a pharmacist before crush/melt or dispersing medication.**

3.11 Twenty-four of the homes reported that they would 'normally' or 'always' seek advice from their pharmacist in such circumstances, three said that they would 'regularly' take such advice. The remaining three homes referred to taking advice on an 'as and when necessary' basis from the pharmacy. Several managers reported that the pharmacist was very helpful in providing guidance about alternative forms of medication which were available and this proved useful in discussing service users' medication regimes with their GP. There were a number of examples of individual circumstances when additional advice would be taken for example if there is difficulty in dissolving medication.

3.12 Reference was also made to service users being discharged from hospital with changes to their medication regime for example instructions supplied to 'crush' certain medication which had previously been available in a liquid form prior to the resident's admission to hospital. Two managers expressed concerns about the impact of changes that were made to a resident's drug regime when they were admitted to hospital after it had been agreed policy to use liquid medication when administering drugs to service users who had some form of dysphagia.

- **Experience of getting authorisation /advice from doctor or pharmacist**

3.13 All homes reported good experience in seeking advice from a pharmacist. All, except two homes, reported positive experience in respect of gaining authorisation from an individual's GP (although some said the cost factor of liquid medication was an influencing factor). One manager reported that a change of medical practice had helped considerably in improving the working relationship with the GP. One manager reported very positive experience of a 'local enhanced service' trialled in Sheffield where GPs had received additional payments for providing an enhanced service to the care home and service users. This has led to the GP holding weekly surgeries in the home, conducting more regular medication reviews and being more available to discuss the emerging and changing needs of service users in the home. The Manager felt that this had been particularly helpful when service users encountered swallowing difficulties because of the closer understanding that the surgery had developed of service users' needs.

3.14 Two other managers reported changes over recent years moving from the care home working with a number of GP practices to the vast majority of service users being registered with one practice. They felt that this had led to improved understanding and the GP practice being prepared to give a better service to the home (for example holding regular surgeries in the home) and giving more attention to service users. One manager worked with three separate practices referring to the need (wherever possible) to retain the service users' previous GP prior to admission and raised concerns about the perceived risk of 'collusion' in the prescription of medication if there was only one GP practice supporting the home.

3.15 One care home referred to their local clinical commissioning group having a pharmaceutical adviser who could be contacted for further advice on medication issues in care homes. They confirmed that they had contacted the pharmaceutical adviser on more than one occasion and had found it very useful to take advice from an impartial party in a variety of different aspects of the administration of medication.

3.16 One of the recommendations highlighted in the key research report 'care homes use of medicines' (CHUMs) study compiled for the Patient Safety Research Portfolio for the Department of Health (Alldred et al 2009) was the suggestion that having a preferred GP provider would be of benefit in improving the use of medicines in care homes. The 'local enhanced service' as described in Sheffield puts this model into practice and was described as leading to improved medication reviews and working relationship with the home in respect of drug prescription and monitoring arrangements.

- **Level of awareness of different medicines which should not be dispersed or crushed**

3.17 All, except two, of the care homes contacted quoted awareness of problems that could be presented and 17 of the care homes reported that this area was covered in induction training for all staff. However, when this question was pursued the majority of the managers had limited knowledge of the various problems that could be presented. For example five managers acknowledged that they knew crushing or melting medication was often undesirable but had limited understanding of the effect of such action on medication and would rely on advice from the pharmacist. Six of the managers (one fifth of those surveyed) had a good level of knowledge and were able to quote all the examples given in the questionnaire. Managers also reported that increased knowledge had led to them raising issues about crushing, melting

or dispersing medication. For example, one manager quoted an example of a GP giving authority for Epilim (a treatment for epilepsy) to be crushed, despite the medication being enteric coated (an enteric coating is designed to help protect drugs from the acidity of the stomach).

3.18 The two most common areas that managers were aware of was a) the impact on medicines where a small change in dose can increase the chances of side effects, and b) medicines which are coated to disguise the taste.

3.19 The results of this survey suggest that there is an awareness of the impact of crushing, melting or dispersing drugs but that regular training in this area is necessary to ensure there is a proper awareness of the potential impact of altering medication in these ways.

- **How frequently were medicines mixed with food to make them easier to administer?**

3.20 In 22 of the homes surveyed this was a daily occurrence. Frequently foodstuffs had the product 'thick and easy' combined to improve the texture and make them easier to swallow. Five others reported that this depended on the needs of the service users affected but had been a daily occurrence in the past (not at present). Three of the homes reported that this would be considered if necessary but was not happening at present.

3.21 The widespread nature of this practice as demonstrated in this survey suggests that such practices are common in a significant proportion of care homes. It is important that service users remain aware that medication is being administered to them in this way. It also raises the risk of service users receiving the medication covertly without additional safeguards being in place (see Section 3.30 and 3.31 below).

- **How frequently were doses missed because carers had to wait for them to melt**

3.22 None of the homes reported this as a problem which had arisen but commented that some forms of medication had been more difficult than others to dissolve. Six of the managers referred to the need to prepare certain medication at the beginning of the medication round. This meant that the round took longer but was part of the process of preparation.

- **How frequently do carers hold off giving doses because it is difficult to administer them**

3.23 Three homes reported that this had never happened but the others reported that this happened on occasion because of service users' medical conditions, short-term illnesses and days when different service users were 'struggling'. A regular problem reported was service users spitting tablets out or refusing to take them. One manager referred to medication rounds taking longer because individuals might refuse their medication. Different strategies would be used including returning to service users more than once to see if they were more willing to take the medication.

3.24 Individual medication such as Adalat (this drug is used to treat high blood pressure and angina and there is no liquid form of this medication) and Movicol (a laxative) were quoted as examples which presented problems. Homes reported such information being recorded on the MAR (medication administration record) sheet where service users for example refused

to take the medication or spat it out. Just over 50% of the homes said that where this happened twice this would lead to them contacting the GP for further advice, requesting a medication review or considering a referral through the GP to the Speech and Language Therapy (SALT) team.

3.25 Two managers said that having to hold off giving doses had become an 'ongoing daily challenge' due to the dependency level of service users in the home. The strategy of staff would be to go back and try again. In one of these homes the GP now holds a full surgery once a week and this had made it easier to review a resident's medication regime.

3.26 A high proportion of care staff time in a care home is involved with medication. Alldred et al (2009) in the CHUMS study for example observed that care home staff spend 40-50% of their time on medicines related activity. One manager referred to recent concerns having arisen about the impact of missed doses affecting a resident taking anti-epileptic medication. The resident had on occasion been unwilling to take Epilim tablets but this had been addressed when she was prescribed the drug in a liquid form.

3.27 It is important to note that any occasions on which medication is intentionally withheld or refused by a resident should be recorded immediately and signed by the staff member charged with administration of the medication. Care workers who fail to give medication as prescribed or fail to give medication at the right time leave themselves open to the allegation of 'wilful neglect'.

- **Protocol for covert administration of medication**

3.28 The 'covert' administration of medication refers to situations in which medicines are administered in a disguised format without the knowledge or consent of the person receiving them.

3.29 Twenty seven of the homes reported having a specific protocol (or procedure) for the covert administration of medication, three did not. One home (which did not have a policy) referred to the need for very careful recording of the circumstances under which it was necessary and the reasons underpinning the decision. The three homes which did not have a protocol acknowledged that the availability of such a protocol would be most useful for their staff. One home reported they had a policy of not admitting people with dementia and that they would object in principle to giving medication covertly to a resident even if such a practice was approved by the resident's GP.

3.30 Guidance from the National Institute for Health and Care Excellence (NICE 2014) suggests that there are some circumstances in which covert administration is necessary but it should never be used for service users who have capacity to make decisions about their own medical treatment. The guidance further recommends that care home providers should have a process in place for covert administration of medicines and this should be recorded in the care home medicines policy. The guidance goes on to suggest that commissioners and providers should consider having a wider policy on the covert administration of medicines.

3.31 The NICE guidance sets out certain key elements that should be included in the process for covert administration of medicines (2014: 30). The key elements include:

- Assessment of mental capacity;
- Holding a best interests meeting involving care home staff, the health professional prescribing the medicine(s) pharmacist and family member or advocate to agree whether administering medicines without the resident knowing (covertly) is in the resident's best interests;
- Recording the reasons for presuming mental incapacity and the proposed treatment plan;
- Planning how medicines will be administered without the resident knowing;
- Regularly reviewing whether covert administration is still needed;
- Discussing the treatment plan with care home staff, relevant health professionals (including a pharmacist) and the family members or carers of the resident, or advocate (nominated representative), unless it is clear that the resident would not have wished this and a record of the discussion is made;
- Regular reviews of the need for continued covert administration of medicines.

➢ **Awareness of the relevant legislation relating to covert administration**

3.32 All homes reported some level of awareness of this with a variety of answers being given. 29 of the homes reported that they would not sanction the step unless it was given approval by the prescribing doctor (as previous referred to one manager stated that this had never been considered in their home due to the admission criteria). The most common response was that medication should only be given covertly when it was in the best interests of someone who lacked capacity and was approved by the GP and family.

3.33 The Royal College of Psychiatrists issued a College statement on covert administration of medicines in 2004. This made clear that whenever such a step was considered 'there must be a clear expectation that the patient will benefit from such measures, and such measures will avoid significant harm to the patient or others'. The statement recommends that the proposed treatment plan should be discussed with a relative, carer or nominated representative 'unless it is clear that the patient would not have wished this'. It further recommends that the proposed treatment should be discussed with a pharmacist to ensure that medication may be mixed with food and will not be affected by procedures such as crushing.

➢ **Awareness of circumstances where it would be lawful to administer medicines covertly.**

3.34 The responses to this question represented a rehash of the responses to the previous questions. The homes again referred to having to act in the "best interests" of service users referring to the need for a mental capacity assessment on occasion. 22 of the homes stated their understanding that this was only lawful where someone lacked capacity and was unable to give informed consent. Several managers referred to referring closely to the home's procedure which involved consultations with the resident's family and GP and the need for a mental capacity assessment to be undertaken.

3.35 It is positive that the majority of homes contacted were aware of the circumstances under which it would be acceptable to covertly administer medication to a service user. However, a significant minority of the care homes were not fully aware of these circumstances.

- **In your view who has the authority to authorise medicines to be administered covertly?**

3.36 The vast majority of the homes said that the doctor had the authority if it was felt that someone lacked capacity. A number of homes used a mechanism whereby a meeting was held which involved the resident's family, the GP and the Care Manager who had been involved in funding for the placement. In these circumstances this was a shared decision – one of the care homes referred to these as a "best interests" meeting reflecting the terminology used in their medication policy. Many managers said that arranging these meetings could be difficult due to the time demands on GPs or care managers.

3.37 In instances where the covert administration of medicines is being considered a first step should be to establish whether the affected individual has sufficient mental capacity to refuse medication. The guidance from NICE on managing medicines in care homes makes clear that in some circumstances covert administration of medication is necessary but it should never be used for service users who have capacity to make decisions about their medical treatment.

3.38 One home referred to the difficulty presented by people who were paying privately and as a consequence did not have a care manager. One referred to one resident who had a solicitor managing their finances but who was not 'qualified' to offer an opinion about the medication. This individual had no family so the decision to administer medication covertly was made by the GP in isolation. This is at odds with the NICE guidance which stipulates that for service users who lack capacity the decision for covert administration of medicines should not be undertaken without being discussed with care home staff, relevant health professionals (including the pharmacist) and the family members, carers or an independent advocate on behalf of the resident.

- **When would you consider covertly administering medicines?**

3.39 The majority of the homes referred to situations where the resident lacked capacity and failing to take the medication having a detrimental effect on the resident as leading to the need to covertly administer medication. All of the homes referred to this arising where someone had dementia and was unwilling to take their medication.

Two homes referred to this occurring where the GP had given approval or where it was important for the service users to take the medication 'for their comfort'. These homes did not explicitly refer to someone lacking capacity to make a decision about taking the medication.

3.40 Several homes referred to this becoming a difficult area because of the emerging understanding of the Deprivation of Liberty Safeguards (DoLS). For example one manager referred to the local authority have been 'inundated' with requests for a DoLS assessment with the result that it was taking 'several weeks if not months' for the assessment to be made.

3.41 The delays in obtaining DoLS assessments raises the possibility of a service user being covertly administered medication in the absence of a capacity assessment due to the time-sensitive nature of the concerns relating to medication issues.

- **Did the care home have a protocol for administering medication to residents with dysphagia?**

3.42 Three of the homes had a specific protocol or policy in respect of administering medication to service users with swallowing difficulties. One of the homes had been actively considering this throughout its organisation after an incident in which a resident with swallowing difficulties had died after choking (the home was not found to be in any way at fault in this incident).

3.43 All of the homes said that they would find such a protocol/procedure useful in guiding their decision in relation to service users who had some form of swallowing difficulties.

- **Did the care home have blanket permission to crush /disperse /melt medicines from the doctor(s) who provide care to the home or from any resident's relatives?**

3.44 None of the homes had obtained a blanket permission from relatives or a GP for this practice. Such decisions were taken on a 'case by case' basis. Many of the managers said that they would not consider this acceptable and said that in their experience a GP would not be willing to give blanket permission in this way.

3.45 It is positive that none of the homes involved in the survey had made arrangements to obtain a blanket permission to crush, disperse or melt tablets. Such an approach would be inappropriate given the range of impact on different medication of adopting such practices.

- **Were care homes aware of the laws regulating the administration of medication?**

3.46 All of the Homes surveyed referred to an awareness of these and having received training but were unable to refer to specific legislation. The management and administration of medicines in care homes is covered by the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 and the Human Medicines Regulations 2012 in England. The registered person for a care home is expected to protect service users against the risks associated with the unsafe use and management of medicines, by means of the making of appropriate arrangements for the obtaining, recording, handling, using, safe-keeping, dispensing, safe administration and disposal of medicines use for the purposes of the regulated activity.

3.47 It is recommended that staff in care homes should be reminded of the laws relating to the administration of medication together with their individual responsibility under a 'duty of care'. Such reminders should be covered during regular refresher training in medication management.

- **How confident were homes about their knowledge regarding the laws which allow someone to crush/disperse/melt medicines?**

3.48 This question produced a variety of responses. Two of the home managers said that they were not aware of any specific requirements in respect of this and one said that they had a 'layman's understanding'. The majority said that they felt that as long as they were taking the action under the direction of a GP that this was acceptable. One said they were confident in their knowledge but was unable to place this in context of what the specific legal requirements were. One said that they understood this to be acceptable as long as it was being done on an

individual basis, it was a method of last resort because the patient was unable to take the medication ordinarily, the patient must retain the right to refuse the medication and the action was being taken under the direction of the GP.

3.49 Guidance produced by the Royal Pharmaceutical Society (2011) advises on the importance of recognising the potential consequences of manipulating a medical product. This guidance also makes clear that there are certain types of dosage which should never be split or crushed. In circumstances where medication has been crushed or split this represents an unlicensed use of the medicine and this will mean that the pharmacist supplying the medicine may assume additional responsibility and liability for the decision to crush or split the dosage form.

3.50 The Department of Health publication (2004) intended to improve medication safety in the NHS highlighted that the safe handling of medication within care homes will be determined by the extent of training for staff. Given the low level of knowledge of the laws relating to the crushing, dispersal or melting of medication and the associated low levels of awareness of the potential impact of these actions this is highlighted from this survey as a key training need for refresher training for care staff (see paragraph 7.4).

- **How confident were homes of the requirements of the regulator in relation to administering medication?**

3.51 29 of the homes were regulated by the Care Quality Commission and 1 by the Care and Social Services Inspectorate Wales. The managers described themselves as confident about the requirements of the regulator but gave different answers to the question. None of the managers questioned could supply chapter and verse details of the requirements of the regulator. Two of the homes had access to a form of internal audit undertaken by their organisation. This audit monitored practice against the requirements of the regulator in respect of record keeping, storage, administration and disposal. Four of the homes received regular audits from their supplying pharmacist (Boots).

3.52 Many of the managers reported that CQC had been giving increasing attention to medication practices during recent inspections. The areas of focus included staff training, the accuracy of the medication administration record sheets (MARS) and the policies in place. One home had received a very recent inspection and said that the inspector had referred to the guide produced by the National Institute for Health and Care Excellence in 2014.

3.53 One manager referred to seeking clarity on certain medication practices from CQC and said that they were unwilling to give any specific guidance advising that this was the responsibility of the home with advice from their pharmacist where necessary. She felt that clear guidance would be helpful since there was a risk of individual interpretation by inspectors.

- **Have you or your staff been actively trained in administering medicines to residents with dysphagia in the last 5 years?**

3.54 Only 6 of the 30 homes had received training in this area. Four of the homes had received this training through their pharmacy, one home received yearly update training for staff supplied by a local NHS trust and one had access to training which was organised centrally and delivered by a member of the local Speech and Language Team (SALT).

3.55 The training arrangements as described were piecemeal with no clear consistent route for staff to be made aware of how to meet the needs of service users with dysphagia.

- **If a resident is seen to be chewing a medicine is this likely to be reported?**

3.56 All homes reported that this would be raised along with a variety of other concerns such as someone who has had a stroke, is bringing up food, is sucking their medication or coughing when attempting to eat or take medication.

- **Do you actively look for swallowing problems in your residents?**

3.57 All homes reported that this is an issue which is regularly reviewed with action taken when there is evidence that someone appears to have difficulty swallowing triggering a review. Homes reported a variety of experiences in making referrals for an assessment from the local Speech and Language Therapy (SALT) team. Some reported receiving prompt assessments with someone visiting within 'a couple of working days' but others reported waiting up to two weeks before receiving a visit. Three managers stated that the response was largely reliant on the degree of urgency placed on the assessment by the referring GP.

3.58 Although all the homes contacted reported that swallowing difficulties was an issue which is routinely reviewed the numbers of people they reported to be affected by this condition overall was lower than might be expected (ref: Rosenvinge and Starke 2005). This suggests that there could be a lack of overall awareness amongst care staff of the symptoms of dysphagia leading to an under reporting of the number of service users affected.

- **When you identify a new resident with swallowing difficulties what actions would you take?**

3.59 Respondents were asked to identify which of the following actions they would take when identifying someone with swallowing difficulties:

- Seek a professional assessment of the swallow;
- Identify the types of food which are most easy for them to swallow;
- Identify how best to administer their tablets and capsules ;
- Tell their relatives;
- Tell their doctor;
- Ask for a review of their medicines by the doctor; and,
- Ask a pharmacist what different medicine options are available.

3.60 Managers reported taking the majority of the actions described although one raised particular concerns about obtaining a professional assessment of the swallow from the SALT team due to the delays they had encountered. A review of medicines was consistently requested although the majority of the homes reported that the cost of liquid forms of medication was a concern to GPs in their prescribing practices. One of the homes had arranged for one member of staff to receive additional training in dysphagia so that she could become a

resource for the staff team. This step was taken in direct response to a significant increase in the number of people in the home with swallowing difficulties.

- **Are there any barriers to providing the most appropriate medicines for residents who are unable to swallow safely?**

3.61 Most of the homes reported no specific barriers but ten homes referred to the cost of liquid medication being a barrier with budget concerns influencing the behaviour of GPs. One home felt that budgetary concerns had led to their GP actively discontinuing certain medication. Homes also reported certain medication not being available in a liquid form as a challenge (whilst acknowledging that that this had improved considerably in the last 10 years) and particular problems in administering medication to people receiving end of life care. Three homes also reported problems in respect of service users who were subject to a PEG feeding regime and the additional challenges this could present.

3.62 One of the homes reported a particular problem with a resident who would not drink fluids which included a thickening agent. However they had a tendency to aspirate on 'more watery' fluids.

- **Do you have a protocol for residents who refuse their medication?**

3.63 Only three of the homes did not have a specific policy in this area. Amongst the remaining homes practices varied but consistent elements included any missed doses being recorded on the MAR sheet, a follow up being made with the GP and further advice would be sought from the pharmacist.

3.64 It was positive that the majority of homes had a specific policy in place to cover situations in which service users refuse to take their medication. However as highlighted in Section 3.27 of this report it is important to note that any occasions on which medication is intentionally withheld or refused by a resident should be recorded immediately and signed by the staff member charged with administration of the medication.

- **If 'No,' would such a protocol be useful to you or your staff?**

3.65 Those homes which did not have a specific policy referring to service users who refuse their medication said that the availability of such a protocol would be very useful. Three managers said that despite having an agreed practice in their home it would be useful for a standard CQC approved protocol to be made available to guide practice in this area.

3.66 Arrangements to follow up the refusal of medication by a service user is an important safeguard for both service users and the care home in such circumstances. In the case of a care home failure to adequately follow up such circumstances could lead to an allegation that a care worker (and by extension the care home) was not properly discharging their duty of care to the service user. Amongst the underlying reasons for refusal could be swallowing difficulties encountered by the service user.

## 4. Conclusion

4.1 The findings of this study support earlier studies which found that a high proportion of care home residents are affected by swallowing difficulties.

4.2 Despite the high numbers of people affected, recognition of the problem and knowledge of the steps to take in response is patchy and demonstrates a need for effective training in this area for staff working in care homes.

4.3 Amongst the particular issues highlighted is how to ensure that residents with swallowing difficulties continue to receive prescribed medication which may on occasion involve altering the form in which the medication has been prescribed. For many this may involve medication being prescribed in a liquid form but considering the best arrangement should involve discussions between the staff in the home, the person's GP, the community pharmacist, the individual affected and their relatives. Although budgets will often play a part in reaching a clear conclusion about the steps to be taken in response this should not be the paramount consideration rather how the individual's needs can best be met through effective prescription and administration arrangements.

4.4 A number of ways in which the care and support of people with swallowing difficulties in care homes could be improved has been highlighted in this report and they are summarised in the recommendations section.

4.5 The quality of care will only improve if agencies work together to improve care practice provided to people affected in this way. We therefore make the following recommendations which are separately directed at the management of care homes, Clinical Commissioning Groups and the Care Quality Commission.

## 5. Recommendations

It is recommended:

**To Care Homes**

**Recommendation 1:** all staff in care homes are trained in the safe administration of liquid medication.

**Recommendation 2:** all care homes ensure they have relevant policies and procedures covering the administration of liquid medicines.

**Recommendation 3:** staff in care homes always seek advice from the service user's GP and community pharmacist when the person encounters difficulties in swallowing tablets or capsules and this should be recommended in the care home's relevant policies and procedures.

**Recommendation 4:** as good practice, care homes should ask the prescribing GP to confirm their authorisation in writing by, for example, signing the service user's case record to confirm authorisation as was found to be the practice in some of the care homes surveyed.

**Recommendation 5:** awareness of the risks of crushing, melting or dispersing drugs is covered in induction training for all staff and is one of the topics covered in annual refresher training for staff in medication practice.

**Recommendation 6:** Circumstances in which medication is mixed with food prior to being administered should be recorded on the service user's care plan and noted on the medication administration record. Care staff should also take care to record potential reduced or missed doses where a resident has been unwilling or unable to consume a whole portion of food which has been mixed with medication.

**Recommendation 7:** On any occasions when medication is intentionally withheld or refused by a resident should be recorded in the medication administration record (MAR) and signed by the staff member responsible for the administration of the medication. This expectation should also be included in care home's relevant policies and procedures.

**Recommendation 8:** In line with the guidance issued by NICE in 2014, all care homes should include a section in their medication policy setting out the circumstances under which covert administration of medication would be considered and the process to be followed prior to such steps being taken.

**Recommendation 9:** The approach to the covert administration of medication which is to be set out in each home's medication policy must be the subject of refresher training in medicines management for all staff. The policy should include detailed guidance to staff on the steps to be followed and should, as a minimum, include the detail set out by NICE in 2014.

**Recommendation 10**: As a minimum, in instances where covert administration of medication is being considered, the affected service users should always receive a mental capacity assessment in advance of discussing this matter. Where a service user has been found to lack capacity then an Independent Mental Capacity Advocate (IMCA) should be appointed to support the service user and advocate on their behalf in any meetings or discussions held to determine whether administering medicines without the resident knowing is in the resident's best interests.

**Recommendation 11:** Given the reported incidence of service users with dysphagia in care homes it is recommended as best practice that care homes should have a written protocol describing the arrangements to be made for administering medication to service users with dysphagia.

**Recommendation 12:** Given the high reported incidence of dysphagia amongst service users in care homes and the proportion of time spent dealing with medication related matters it is recommended that all staff should receive training in administering medicines to service users with dysphagia.

**Recommendation 13:** It is recommended that care home staff should receive training in recognising the symptoms of dysphagia to increase awareness and improve treatment of service users affected by dysphagia.

**Recommendation 14:** It is recommended that care homes should include guidance in their policy on the actions which should be taken in circumstances where a service user refuses medication.

**To Clinical Commissioning Groups and Local Authorities**

**Recommendation 15:** When determining medication arrangements for people with dysphagia in care homes it is recommended that the best form of treatment for the individual service user should be the primary consideration rather than decisions based on cost.

**Recommendation 16:** Clinical Commissioning Groups should study the applicability of the Sheffield 'local enhanced service' approach in their area as a possible model for improving medication review and prescription arrangements in care homes.

**Recommendation 17:** Given the potential seriousness of care home service users missing medication doses it is recommended that completion of a Deprivation of Liberty Safeguards (DoLS) assessments in circumstances where covert administration of medication should be treated as a high priority.

**Recommendation 18:** Clinical Commissioning Groups should compile best practice guidance on administering medication to service users with dysphagia to guide prescription practice and assist homes in compiling written protocols.

**Recommendation 19:** Clinical Commissioning Groups should give consideration to compiling 'best practice' guidance for steps to be followed in circumstances where service users refuse medication to guide the approaches to be adopted in care homes.

**To the Care Quality Commission**

**Recommendation 20**: The Care Quality Commission (CQC) should make arrangements to review medication practice in relation to people with dysphagia in care homes as part of a future targeted programme.

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## Appendix: Survey of medicines related care of residents with dysphagia

1 How many residents do you have in your home?

2 Do you have any residents/Patients with swallowing difficulties?

Yes/No

3 If so how many are affected in this way

4 How frequently do you have to do the following?

- Crush tablets
- (Daily, more than once a week, weekly, monthly) (delete what does not apply)
- Melt or disperse tablets before administration
- (Daily, more than once a week, weekly, monthly) (delete what does not apply)
- Split tablets
- (Daily, more than once a week, weekly, monthly) (delete what does not apply)

5 If you have to crush/melt or disperse tablets how often do you get authorisation from a doctor?

6 Before you have to crush/melt or disperse tablets how often to you first seek advice from a pharmacist?

7 What is your experience of trying to get authorisation from a doctor or advice from a pharmacist in such circumstances?

8 Are you aware of different medicines which should not be crushed/dispersed or melted (tick those which apply based on response to question)

- Medicines where a small change in dose can increase the chances of side effects
- Medicines which are designed to delay the release of the drug into the body
- Medicines which are coated to protect the drug
- Medicines which are coated to protect the stomach
- Medicines which are coated to release the drug after the stomach
- Medicines which are coated to hide the taste

9 How frequently do you have to mix medicines with food to make them easier to administer?

(Daily, more than once a week, weekly, occasionally) (delete what does not apply)

10 How frequently do you think you might miss giving doses because you have to wait for them to melt?

11 How frequently do you hold off giving doses because it is difficult to administer them?

12 Do you have a protocol for covert administration?

Yes/No

13 If ‘No’, would such a protocol be useful to you or your staff?

| |
|---|
| 14 Are you aware of the relevant legislation relating to covert administration of medication? |
| |
| What do you understand to be the requirements of the legislation? |
| |
| 15 What circumstances are you aware of where it would be lawful to administer medicines covertly to a resident? |
| |
| 16 In your view who has the authority to authorise medicines to be administered covertly? |
| |
| 17 When would you consider covertly administering medicines? |
| |
| 18 Do you have a protocol for administering medicines to residents with dysphagia (difficulties in swallowing)? |
| Yes/No |
| 19 If 'No,' would such a protocol be useful to you or your staff |
| |
| 20 Do you have blanket permission to crush/disperse/melt medicines from the doctor/s who provide care to your home? |
| Yes/No |
| 21 Do you have blanket permission to crush/disperse/melt medicines from any individual patient's relatives? |
| Yes/No |
| 22 How would you describe your awareness of the laws that regulate the administration of medicines? |
| |
| What particular requirements are you aware of that arise from these laws? |
| |
| 23 How confident are you of your knowledge regarding the laws which allow you to crush/disperse/melt medicines? |
| |
| If you are confident, what are the particular requirements that you are aware of? |
| |
| 24 How would you describe your awareness of the requirements of your social care regulator (CQC, CSSIW, SCRC, RQIA) in relation to administering medicines? |
| |
| What requirements are made by the regulator? |
| |
| 25 Have you and your staff been actively trained in administering medicines to residents with dysphagia in the last five years? |
| |

| 26 Under what circumstances would a resident be reported to be having swallowing difficulties (what would suggest that they might be experiencing problems in swallowing)? |
|---|
| |
| 27 Do you actively look for swallowing problems in your residents? |
| |
| 28 When you identify a resident with swallowing problems what actions would you take? (tick all of the steps described by the respondent):<br>• Seek a professional assessment of the swallow<br>• Identify the types of food which are most easy for them to swallow<br>• Identify how best to administer their tablets and capsules<br>• Tell their relatives<br>• Tell their doctor<br>• Ask for a review of their medicines by the doctor<br>• Ask a pharmacist what the different medicine options are available |
| |
| 29 Are there any barriers to providing the most appropriate medicines for residents who are unable to swallow safely? If 'yes' please describe what these are. |
| |
| 30 Do you have a protocol for residents who refuse their medication? |
| Yes/No |
| 31 If 'No,' would such a protocol be useful to you or your staff |
| |

## Acknowledgments:

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## Publications by The Patients Association:

Patient Stories (2013, 2012, 2011, 2010, 2009)

Waiting Times Report: Crunch time (July 2015)

Time to Act – Urgent Care and A & E: the Patient Perspective (June 2015)

PHSO: Labyrinth of Bureaucracy (March 2015)

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## *The Patients Association's Mission Statement*

*The Patients Association is a healthcare charity which for 53 years has advocated better access to accurate and independent information for patients and the public; equal access to high quality health care for patients; and the right for patients to be involved in all aspects of decision making regarding their health care.*

*By listening to patients, we are able to campaign to improve services. We will work with all healthcare providers to improve services. Very often patients think they are alone with the problem or complaint they have. When patients talk to us we are able to track problems arising in more than one place and realise there is a nationwide issue that needs change.*

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