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## Supporting people living with dementia and faecal incontinence in care homes

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### The People whose home is a care home

There are approximately 17,500 care homes in the UK which are home to about 487,000 older people, the majority are women aged 80 years or older (Care Quality Commission 2010). As many as 80% of care home residents may have dementia, though this is not always documented, (Gordon et al. 2014). In England the majority of care homes do not have on site nursing provision and rely on community nurse specialists for support when residents require nursing advice and care. The support of people living in care homes is a well-documented problem (Taunton et al. 2005; Heckenberg 2008; Saga 2014) and how well they are managed is often seen as a marker of the quality of care (Care Quality Commission 2010). Faecal incontinence can be a source of distress, discomfort, lead to complications such as skin breakdown and infection and affect an individual's sense of dignity and self-worth. It can also be a challenging aspect of care for those who work in care homes.

### What is faecal incontinence?

One definition of faecal incontinence (FI) is the *involuntary loss of liquid or solid stool that is a social or personal hygiene problem* (Norton et al. 2010). Faecal incontinence isn't an inevitable consequence of aging nor does a diagnosis of dementia preclude the possibility of other health and medical conditions. There are a range of possible causes (see box 1) which can be identified and treated or managed, (Norton & Whitehead 2009; Saga 2014)

Type of faecal incontinence	Description of cause(s)
Overflow incontinence	Secondary to constipation and stool impaction, it often manifests as constant leakage of loose stool or stool-stained mucus (Harari 2009).
Urgency faecal incontinence	A discharge of faecal matter despite active attempts to hold on to bowel contents (Tuteja & Rao 2004) it may be due to weakness in the external anal sphincter (Harari et al. 2004) or diarrhoea resulting from: antibiotics, laxative overuse, lactose intolerance or colorectal cancer (Norton & Whitehead 2009).
Functional incontinence	This occurs when individuals are unable to access the toilet in time, or to manage bowel function and cleaning due to reduced mobility, dexterity, communication or vision. Cognitive impairment may be a cause of functional incontinence (Harari et al. 2004)
Comorbidity-related incontinence	Caused by diseases like stroke, diabetes mellitus, sacral cord dysfunction or by anorectal conditions such as sphincter defects, rectal or vaginal prolapse, rectocele or damage to the pelvic musculature (Harari 2009).
Anorectal incontinence	This is related to anal sphincter dysfunction in later life, often caused by childbearing structural damage to the anal sphincter and pelvic musculature (Harari 2009).
Dementia-related incontinence	Occurring due to a lack of voluntary control by the brain over the external sphincter combined with loss of awareness of the need for continence, misunderstanding the environment and difficulty in communicating needs (Harari 2009). It is related to functional incontinence. Defecation, like the swallowing reflex, is controlled by the brain stem (medulla oblongata, pons and midbrain) (Van Putte et al. 2014) which remain relatively unaffected by most forms of dementia until the final stages (Brettschneider et al. 2015).

*Box 1 – Types of faecal incontinence*

Graham Stokes lists FI as just one issue which can be experienced by people with dementia. This builds on the earlier definition to capture the dementia specific issues that can arise during toileting: *the voiding of urine or faeces either following an unsuccessful effort, or with no apparent attempt to employ an acceptable facility (e.g. toilet, commode, urine bottle)* (Stokes 2013). Box 2 combines possible physical causes with problems commonly faced by people with dementia which can affect their ability to go to the toilet.

Older people living in care homes with dementia may not always recognise the toilet and visual impairment (Faubert 2002; Kavcic et al. 2011) and/or hearing loss (Gordon-Salant 2005; Passow & Hugdahl 2012; Tun et al. 2010) can compound this. An individual's mobility can also reduce the available time for getting to the bathroom and this can be a difficult process if clothing, is not easy to fasten and unfasten.

Definitions of Toileting difficulties (Stokes 2013)
Incontinence - localised physical abnormality (e.g. urinary tract infection, enlarged prostate gland, constipation, cortical atrophy, nocturnal enuresis)
Neuropsychological – due neurological damage from trauma etc.
Sensory disability
Physical disability – mobility and dexterity
Medication effects – sedatives, antidepressants, diuretics, antibiotics
Mood - depression is more common for people with dementia than in the general population
Built environment – distance to the toilet, obstacles, lighting, signage
Social environment – actions and attitudes of others
Psychological factors – personality, habits, life experience

*Box 2 – Issues to consider or address for people living with dementia and faecal incontinence*

### How common is FI among people living in care homes?

There isn't a definitive answer to this question. For the general population aged over 80 years the prevalence of FI is estimated to be between 12% and 22% (Harari 2009), among people who live in care homes the estimate is higher, 40% to 55% (Saga 2014). This variation between CHs may partly be due to differences of definition - faeces contained in a pad might be referred to as FI in one CH and as continence in another. Faecal incontinence is likely to be more prevalent among CH residents living with dementia than in the general population. In a study of primary care patients, the rate of FI diagnosis was four times higher for people with dementia than in a matched group without a diagnosis of dementia, (Grant et al. 2013) but these figures don't differentiate between FI and toileting difficulties. However, FI alone is relatively uncommon. A Norwegian study, that included 980 residents, found that 25.4% of nursing home residents were continent, 31.8% had urinary incontinence alone, 2.6% had FI alone and 40.2% were doubly incontinent, (Saga et al. 2014).

### What can the research tell us?

Most continence research focuses on urinary incontinence, very few studies address FI (Roe et al. 2011; Flanagan et al. 2012; Roe et al. 2013; Flanagan et al. 2014). Recent Cochrane systematic

reviews of FI research have concluded that there are no randomised studies which specifically address the additional problems for people with dementia who live in care homes (Maeda et al. 2010; Norton & Cody 2012; Coggrave et al. 2014). The risk factors for FI are well documented and are summarised in Box 3.

Whilst dementia is frequently mentioned as a risk factor, a recently completed review by this team found only twenty continence intervention studies in care homes that included people with dementia, sixteen of which noted the severity of dementia but not how this affected a person's ability to understand the intervention (Goodman et al in press). There are almost no intervention studies which assess how the dementia trajectory affects toileting issues, for example Hu et al. (1989)

**Having one or more of the problems below is associated with an increased risk of FI for older people**

- Urinary incontinence
- Diarrhoea – possibly due to laxatives, antibiotics, diet
- Multimorbidity or disability
- Faecal loading
- Functional disability
- Cognitive impairment
- Depression

*Box 3 – Risk factors for FI – risk increases with each additional factor*

The Royal College of Physicians' report *Privacy and Dignity in Continence Care Project* (Billings et al. 2009a) identifies various elements which older people consider vital, important or preferable in continence care. At a personal level these include: planning and strategies, when appropriate to conceal and manage the incontinence, regaining a degree of control. Other areas which concerned older people were potential difficulties in understanding staff who spoke with strong accents or for whom English was not their first language and being physically exposed to someone who is the age

of their grandchildren. Being helped by a care worker of the same gender was also important to some older people.

In terms of assistance from care staff these elements centre around the manner of approach: sensitivity to possible embarrassment, maintaining privacy, reassurance, prompt but unrushed assistance, being physically gentle and awareness of personal needs and preferences. Our review of the evidence (Goodman et al in press) has also highlighted that in care homes often it is the most junior and least qualified staff who are responsible for the personal care of residents. It is therefore important that this workforce know their work is valued and important and that they receive additional training and support to address how living with dementia may affect a person's ability to go to the toilet.

### How does living in a Care Home affect toileting and continence for someone living with dementia?

Moving to a care home can be a confusing and lonely experience (King & Johnson 2013; Sieber 2013; Schipper et al. 2015; Theurer et al. 2015), time is needed to learn the layout of the building and become accustomed to communal living (Schipper et al. 2015; Theurer et al. 2015). Meal times and menus will also be different. Continence specialists stress the importance of knowing each individual's normal pattern of elimination before the person's admission to a care home as an integral part of continence assessment. This is often difficult to find out, especially if admission follows a period of deterioration at home or a stay in hospital. What may appear to be FI could be secondary to overflow incontinence from faecal impaction or urgency incontinence from laxatives or antibiotics (see Box 1). Communication with a person with dementia may also be a problem and staff should take time to learn how to interpret an individual's preferences and ways of communicating them. This means that whenever possible, continence assessment should be reviewed regularly and regimes that ensure a resident is offered regular opportunities to use and be taken to the toilet are not abandoned after the first few weeks. Guidelines from the National Institute for Health and Care

Evidence (NICE 2015) provide an assessment algorithm for identifying and treating FI in specific groups, including frail older people and those with cognitive impairment. A report from the Royal College of Physicians (Billings et al. 2009b) highlights the importance of maintaining dignity through a person centred approach to toileting and continence assistance.

### Toileting assistance – staff and staffing

As already noted, care home residents' intimate and personal care (assistance with bathing, dressing, toileting etc.) is usually carried out by staff who often have minimal training in continence and dementia care (Sieber 2013). Taking someone to the toilet who may initially not understand what is happening or resist being sat on a toilet requires dementia specific skills to ensure the person is not alarmed or distressed. Visiting nurses too, need to consider how skilled they are in undertaking a continence assessment with someone who has dementia. Specialist support and the input of family members can optimise their understanding of the issues. When staff turnover in a care home is a problem, then extra care needs to be taken to document what is known about a person's preferences and how they communicate their need to go to the toilet

There is evidence that care staff want to give the best person centred care but feel torn between doing what is right for an individual and getting through the work. This can mean that toileting and intimate care is reduced to a series of tasks that are dominated by the need to fulfil regulatory requirements (Ostaszewicz 2013). Community nurses have a role in working with care home staff to discuss how they can integrate continence care with their everyday personal care work. The importance of providing intimate care should be recognised to support and value care home staff's learning on how to reduce and manage FI.

### Discussion

This paper has set out what needs to be thought about when someone living with dementia also has faecal incontinence. It has outlined the different ways this is defined and what we know about possible causes. A key message from the literature for community nurses visiting care homes is the

need to assess and review how a person's dementia will affect their ability to be continent and how you can support the more junior members of care home staff and ensure that this work is valued by them and their managers.

It is often stated that incontinence is a symptom of advanced dementia and we know relatively little about how dementia affects anal sphincter control or whether it leads to dyssynergia (Reisberg et al. 2006; Van Putte et al. 2014; Harari 2017). We do know however, that it is possible to reduce and manage the number of episodes of faecal incontinence experienced by a person with dementia. This requires nurses and care home staff to learn how to work closely together to achieve person centred continence care that takes account of the many competing demands of care home life.

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