

Improving continence care for people with dementia living at home



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Preface



I am pleased to present this report and guidelines on improving continence care for people with dementia living at home. The needs of people with dementia living at home and trying to tackle this problem, often together with their relatives and close friends, have been little researched. Moreover, much of the guidance available is geared towards the residential care setting. At the same time, professional carers dealing with people with dementia and continence problems

living at home, are not always familiar with the specific issues that people with dementia and their carers face (e.g. in terms of the psychological, social, physical, economic and financial impact). For these reasons, I am confident that this publication will be a valuable resource for people with dementia, carers, health and social care providers, service providers and policy makers alike.

As Chairperson of Alzheimer Europe, I would like to thank all the members of the working group, namely Dianne Gove (Chair), Daniela

Hayder-Beichel, Kai Leichsenring, Vikky Morris, Helga Rohra, Breda Savage, Anthony Scerri and Willeke Sijkpes. The members of the working group had expertise in dementia and/or continence care and came from a variety of professional backgrounds including general practice, nursing, social welfare policy, research, continence clinics, project management and psychology. One member of the group had dementia and another was an informal carer of a person with dementia and continence problems living at home. I would also like to thank the steering committee, Jean Georges, Nicole Huïge, Ivar Næsheim and Paul van Houten, for overseeing the project and contributing towards the development of this publication.

This project was a joint effort between Alzheimer Europe and SCA. Alzheimer Europe is therefore very grateful for the funding received from SCA and for the fruitful collaboration between our two organisations. I hope that readers will benefit from this joint venture and that this publication will contribute towards improving continence care for people with dementia living at home, and in so doing contribute towards social inclusion and promoting the quality of life of people with dementia and their friends and families.

Heike von Lützu-Hohlbein
Chairperson of Alzheimer Europe

1 About the guidelines and our ethical framework

These guidelines were drafted in the context of a joint project by Alzheimer Europe and SCA which extended over two years and involved experts in the fields of dementia, continence, general practice, psychology and policy development, as well as informal carers and people with dementia. The idea arose from the realisation that whilst guidelines for dementia care and for continence care exist, and there are some guidelines for the continence care of people with dementia in residential or nursing settings, there are no such guidelines for the many people with dementia who live at home and experience continence problems.

Due to the lack of research on the specific topic of continence care for people with dementia living at home, an approach based on expert consensus was adopted for the development of the guidelines. This involved the following procedure:

1. Organisation and overview of the process
 - a. Constitution of the steering committee and working group (making sure the right people with the relevant experience and knowledge are involved).
 - b. Constitutive meeting to define the aims, outcomes, timeframe and responsibilities.
2. Review of the literature
 - a. Integrative review of the literature (using research databases but also reports and guidelines) resulting in a synthesis of the findings.
 - b. Identification of key issues based on a discussion of the literature, the expertise of the working group and a brainstorming session.
3. Drafting of the guidelines
 - a. Production and circulation within the working group of a first draft of the guidelines, along with background information.
 - b. Comments and proposed amendments sent to the Chair of the working group for incorporation into a revised draft. Comments for further discussion and different perspectives discussed openly within the group by means of email exchanges and a Skype conference call.
 - c. Further circulation of various drafts and exchange of views coordinated by the Chair until final agreement reached on a draft to be sent out for wider consultation.
4. Wider consultation with relevant stakeholders
 - a. Request for qualitative feedback from purposefully selected small groups of people with dementia, informal carers and healthcare professionals.
 - b. Discussion of feedback by the working group leading to consensus on the final set of guidelines.
5. Publication and dissemination of the guidelines
 - a. Publication and launch of the guidelines at the annual conference of Alzheimer Europe in Glasgow (United Kingdom) in October 2014.

- b. Dissemination of the guidelines: printed copies sent to continence societies and Alzheimer Associations, reports published in electronic newsletters, the Dementia in Europe magazine and on the Alzheimer Europe website, presentations at relevant conferences, overview of the project and resulting guidelines submitted to peer-reviewed journals in the fields of dementia and continence care.

The experts involved in drafting of the guidelines, to whom Alzheimer Europe is immensely grateful, were:

Steering Committee

- Mr Jean Georges: Executive Director, Alzheimer Europe, Luxembourg
- Ms Nicole Huige: Strategic Market Development and Public Affairs Manager, SCA, Gothenburg, Sweden
- Mr Ivar Næsheim: Commercial Director, SCA, Denmark
- Dr Paul van Houten: Care of the Elderly Physician, expert in continence care, Zonnehuisgroep Amstelland, Amstellveen, the Netherlands

Working group

- Dr Dianne Gove (Chair): Director for Projects, Alzheimer Europe, Luxembourg
- Dr Daniela Hayder-Beichel: Nursing Scientist, Centre for Knowledge Transfer in Healthcare, Schriesheim Germany
- Mr Kai Leichsenring: Researcher, European Centre for Social Welfare Policy and Research, Vienna, Austria
- Dr Vikky Morris: Care of Older People Consultant Physician, Musgrove Park Hospital, Somerset, United Kingdom and responsible for the Dementia and Older Person Continence Clinic
- Ms Helga Rohra: Chair of the European Working Group of People with Dementia, Germany
- Ms Breda Savage: Family carer, Ireland
- Mr Anthony Scerri: Assistant lecturer, Department of Nursing, Faculty of Health Sciences, Msida, Malta
- Ms Willeke Sijkpes: Continence Nurse and Field Coach, SCA, the Netherlands

We would also like to thank all those who provided constructive feedback in the context of the wider consultation. This included people with dementia, carers, service providers, researchers and health and social care professionals with a clinical and academic background in the management and care of dementia and/or continence problems.

The report is divided into six main sections. In this first section, we explain why, how and by whom the guidelines were developed. In the second section, we provide information about incontinence and dementia and explain how the continence care of people with dementia living at home should be understood in the more global context of the long-term care of people with complex care needs.

Improving continence care for people with dementia living at home

This requires a collaborative approach involving social and health-care professionals in co-operation with people with dementia and, for those who do not live alone, their informal carers. We emphasise the need to consider continence care of people with dementia living at home as the point at which factors related to age, dementia and continence intersect. In section three, we explore the experience and challenges faced by people with dementia and continence problems who live at home, and also those of informal carers. This is followed in section four by statements from people with dementia and their carers respectively (based on the literature and on feedback from members of both groups). These highlight what representatives from those groups need and desire in relation to continence care and in the wider context of their rights as equal and valued citizens. The actual guidelines can be found in section five. These are addressed to a wide audience and written in a style which is hopefully accessible to many people with dementia and their carers. They may also serve as a useful source of support or tool to help health and social care professionals to consider some of the issues which are specific to the continence care of people with dementia within the community setting, as opposed to in residential or nursing care. The report ends in section six where we highlight what we need from

service providers and policy makers if the continence care of people with dementia living at home is to be improved.

This report and the accompanying guidelines are based on a specific approach to care ethics (1). The emphasis is on care as a dynamic process involving a wide range of people who co-exist in the context of relationships and inter-dependencies (people being dependent on each other in different ways) rather than as isolated, autonomous individuals making independent decisions at specific moments in time. Such an approach is particularly relevant in the case of people with dementia whose cognitive abilities gradually decline over time.

Sometimes, continence problems and management lead to situations which represent ethical dilemmas in that people have difficulty deciding what would be the right thing to do or the right way to react. They may have several options, each with different and even competing implications in terms of what is considered right and wrong. The issue of ethical dilemmas is briefly addressed in sections 3 and 5 of this report. A full report and guidance on ethical dilemmas faced by people with dementia and carers can be downloaded at: <http://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice>



2

2 About dementia and incontinence

2.1 The need for guidelines on continence care for people with dementia living at home

Age is the most significant risk factor for dementia but dementia is not an inevitable part of ageing (2). Incontinence is also not inevitable as we age and most older people do not experience it (3).

Incontinence is not a natural consequence of dementia in the sense that continence problems can often be related to environmental factors rather than dementia per se. In the early and mild stages of dementia, incontinence related to problems with mobility, finding the toilet and toileting skills can sometimes be successfully managed (4). With the right level of support, carers can help and facilitate the person with dementia to retain continence and independence for as long as possible. However, incontinence is more common in people with advanced dementia who have more serious cognitive impairment (5). A few studies have found that incontinence plays an important role in decisions to place a person with dementia in residential or nursing care (5; 6). The combination of incontinence and cognitive impairment in people with dementia may be a predictor for institutionalisation¹ (7; 8; 9; 10).

In the case of severe dementia, incontinence can be an inevitable consequence of complete care dependence and loss of cognitive function (4).

There is a general shortage of research into older people with incontinence and dementia. There is some literature about continence care and the prevalence of incontinence amongst people with and without dementia in the residential care setting but remarkably little about people with dementia and incontinence living at home (11). As explained in the section on “facts and figures”, reliable statistics on the number of people with dementia living at home with continence problems are lacking (11). However, 73% of people with dementia in developed countries live at home (12). The way that continence care is provided in residential care settings by professional carers cannot simply be transposed from that setting to the home. Some people with dementia live alone and others with relatives or friends who provide care and support but are not trained or paid to do so. Guidelines on continence care for people with dementia living at home are needed.

- > *Dementia is not an inevitable consequence of ageing.*
- > *Incontinence is not an inevitable consequence of ageing.*
- > *In severe dementia, incontinence is an inevitable consequence of complete care dependence and loss of cognitive function.*
- > *There are many interventions to help people with dementia retain continence and independence as long as possible.*
- > *Most people with dementia live at home.*
- > *Little is known about the experience and needs of people with dementia who have incontinence.*

2.2 What we mean by dementia and continence/incontinence

This report and the guidelines are relevant to people with dementia experiencing continence problems at home. For most people, “home” means their own house, apartment or other form of accommodation, purchased, rented or free, where they live alone or with other people. The living situation of some groups of people has not been specifically addressed in these guidelines due to a lack of available information and expertise. This includes, for example, homeless people, travellers and people who are in prison.

Most people reading this report probably already have some knowledge about dementia and incontinence but may be unclear about the difference between dementia and Alzheimer’s disease or about different terms used in connection with incontinence and continence. We will therefore briefly explain these terms.

2.2.1 Dementia

“Dementia” is the term used to describe a syndrome or set of symptoms with multiple aetiologies (causes), typically involving loss of memory, mood changes and problems with thinking, orientation, comprehension, calculation, learning capacity, language, and judgement (13). It is an umbrella term which describes the symptoms, usually of a chronic or progressive nature, which occur when the brain is damaged as a result of one or more illnesses (14). Although it is not, strictly speaking, a disease, it is often referred to as such and most types of dementia (of which there are over a hundred) are caused by or associated with a specific disease. Approximately half of all people with dementia have Alzheimer’s disease (AD) (15), followed by vascular dementia (with or without Alzheimer features) and dementia with Lewy bodies (16). In some cases, a person can have brain changes linked to all of these conditions.

People with dementia may experience physical, behavioural and psychological difficulties, have difficulty carrying out various everyday tasks and become increasingly dependent on others as the condition progresses. Dementia is often described as involving three or more different stages with certain symptoms being more common at certain stages (e.g. mild, moderate and severe) (17). Despite a lack of reliable statistics, incontinence is generally associated with the latter stages of dementia. With Alzheimer’s disease, for example, its occurrence has been found to increase as the disease progresses (18). However, people with dementia do not form a heterogeneous group and do not all experience the same symptoms, in the same order or to the same extent.

The way that a person is affected by dementia may be influenced by personal factors, coping skills, the way that society is organised and the way in which people with dementia are treated. These factors exist in addition to neurological impairment (19; 20).

¹ The term “institutionalisation” is being used in this report to refer to the move or necessity to move into residential care settings such as nursing homes or care homes. It should not be understood as implying any judgement on the quality of care provided in such homes.

Dementia is often considered a disability. According to the United Nations Convention on the Rights of Persons with Disabilities (21), people are considered as having a disability if they have “long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (2006, article 1). People with dementia represent the largest group of people with long-term care needs. Those who also experience continence problems are at risk of being further restricted in their daily activities, in socialising and in maintaining an active role in the community and are thus in need of long-term care and support.

Dementia involves the progressive loss of various skills, not a “once and for all” global loss affecting all areas of a person’s life. Moreover, there may be fluctuations in ability based on a range of factors (e.g. linked to the environment, other people and the situation) and it is important to consider when support is needed and can be provided, and whether supported or substitute decision making would be more appropriate. Due to the “task-situation-person-specific” nature of capacity, we have deliberately emphasised the need to try to involve people with dementia in decisions relating to their care because in many cases, they will be able to participate in decision making.

When people still have capacity to make decisions regarding specific care issues, it is essential to consider their future wishes and these can be discussed or written in an advanced care plan. Advance care planning discussions can provide a possibility of clarifying future directions and choices so that: the issues can be raised; examined and fully discussed; fears both trivial and huge can be clarified and addressed; and a more realistic and pragmatic approach can be taken to living life in the way that is important to that individual person (22).

At some point and in certain situations, people with dementia (especially those with advanced dementia) will find it difficult if not impossible to contribute their views, understand and retain information, make reasoned judgments about their condition and care needs, and weigh up risks and benefits. In such cases, someone else may need to make a decision on their behalf and this must be done in line with legal and ethical requirements or complying with an advanced care plan. See box 2 in section 5.2.1. for information about supported decision making.

2.2.2 Continence/incontinence

Continence-related terms

Generally speaking, the term “continence” is understood as indicating no involuntary loss of urine or faeces and “incontinence” as the experience of such loss. More detailed descriptions of dif-

ferent types of incontinence are provided below. In this report, we use the term “continence problems” when referring to difficulties either to remain continent or to manage incontinence although we will sometimes refer to one or the other. “Continence care” should be understood as covering all aspects of detecting, assessing, preventing and managing continence problems.

Different types of incontinence

Urinary incontinence is “any involuntary loss of urine” (23). Four main types of urinary incontinence have been identified:

- urgency urinary incontinence (UUI) which is the inability to hold urine long enough to reach the toilet,
- stress urinary incontinence (SUI) which is leakage of urine when the person sneezes, laughs or coughs or during exercise,
- overflow incontinence which is leakage of small amounts of urine from a full bladder,
- nocturnal enuresis which is any involuntary loss of urine during sleep (i.e. bed wetting).

In addition a person may have an overactive bladder which means that they have a feeling of urgency and an increased need to urinate, frequently either during the day or at night (nocturia), with or without involuntary loss of urine (24).

A combination of UUI and SUI is known as mixed incontinence, whereas a combination of both urinary and faecal incontinence is known as double incontinence.

Faecal incontinence involves the “involuntary loss of solid or liquid faeces” (25). Clinicians often distinguish between three types of faecal incontinence, namely:

- passive incontinence which involves an involuntary discharge of faeces without awareness,
- urge incontinence which involves discharge of faeces despite active attempts at retention,
- seepage which involves leakage of faeces following otherwise normal evacuation (26).

The involuntary loss of faeces as well as flatus (i.e. wind or gas from the intestines) is referred to as “anal incontinence” (23; 3).

Functional incontinence

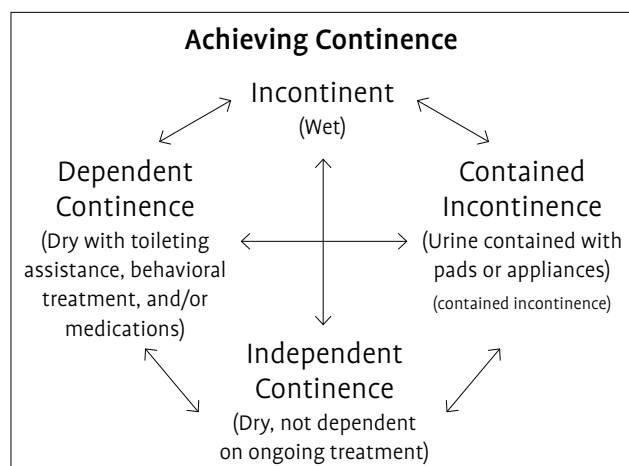
When incontinence has no physiological basis, it is described as “functional”. For urinary incontinence, this involves “the inability of a usually continent person to reach the toilet in time to avoid unintentional loss of urine” (122). This would be the case if incontinence were due to mobility problems, mental impairment or medication. Incontinence may be multifactorial i.e. partly functional and partly due to physiological causes.

Improving continence care for people with dementia living at home

The level of assistance required to achieve continence and manage incontinence

In the latest International Consultation on Incontinence (5th ICI report), Wagg et al. (27) provide a diagram representative of frail older people, which describes a “spectrum of continence” (Figure 1). The implication is that continence can be achieved through assistance, behavioural treatment and/or medication or “contained”, which means that although a person is incontinent, this is managed with pads or appliances.

Figure 1: Achieving continence (from Wagg et al., 2013, p. 1025)



Schmitz, Hayder, Braumann Müller and Saxer (28) developed a similar classification which highlights the importance of understanding whether a person is able to prevent or manage incontinence him/herself or is dependent on other people to do so, which is relevant in planning continence care at home (see Table 1). As the extent and kind of assistance needed may change over time along with the progression of dementia, continence care should be considered in the context of long-term care (see section 2.5).

There are several medical conditions that increase the risk of developing incontinence (3: 27). Below are some examples.

- Diabetes mellitus: People with diabetes commonly experience problems controlling their bladder and bowel. This can happen because of increased weight, nerve damage to the bladder and bowel affecting sensation and thereby decreasing awareness of needing to go to the toilet, overload of urine when blood sugar is too high and due to medications used to control diabetes which can cause diarrhoea.
- Cardiac failure: where the heart is inefficient and fluid can build up particularly in the ankles/legs. This can result in night-time incontinence or affect frequency. Also, treatment of this condition with diuretics (water tablets) can contribute to increased trips to the toilet and occasional urinary incontinence. Also, older people with cardiac failure experience fatigue and going to the toilet may be too much for them.
- Degenerative joint disease and arthritis: this can make it difficult for people to move around or handle clothing easily due to pain or ankyloses (joint stiffness).
- Chronic lung disease: this causes coughing so people with weak pelvic floor muscles can leak urine with stress urinary incontinence or can provoke a micturition in the case of urgency incontinence.
- Parkinson’s disease: This may involve difficulty moving or slow movement making getting to the toilet more difficult and is often associated with over-active bladder symptoms.
- Depression: which can affect motivation for toileting and treatments can affect the bladder/bowels.
- Stroke: which can directly affect parts of the brain related to continence or can result in limb weakness, making toileting more difficult.
- Normal pressure hydrocephalus (NPH): This is a condition, which is associated with both incontinence and dementia. It typically involves a normal or mildly elevated pressure within the brain accompanied by urinary hesitancy or incontinence as well as gait (walking) disturbance and dementia (the latter characterised by mild memory impairment and apathy) (29). Studies suggest that

Table 1: The relationship between incontinence and dependency on self or others (adapted from Schmitz et al., 2010)

Whether/ how continence achieved	Characteristics
Continence	No involuntary loss of urine, no need for support from other people and no use of devices, aids or strategies.
Independently achieved continence	No involuntary loss of urine, no need for support from other people. Necessary measures taken by the person him/herself (e.g. independent use of toileting aids)
Dependently achieved continence	No involuntary loss of urine. Support needed/provided by another person (e.g. for intermittent catheterization).
Independently contained incontinence	Involuntary loss of urine. Necessary measures taken by the person him/herself (e.g. continence aids such as pads and sheets).
Dependently contained incontinence	Involuntary loss of urine. Support needed/provided by another person (e.g. continence aids).
Unmanaged incontinence	Involuntary loss of urine. Support from another person is not available or used. Continence aids are not available or used.

NPH accounts for approximately 6% of all dementia cases and 9% to 14% of people with dementia in nursing homes (30). It is sometimes described as a potentially treatable form of dementia as it can be successfully treated through the surgical implantation of a cerebrospinal fluid shunt (Meier et al., 2004 – in 27). In the past, NPH was only diagnosed when all three cardinal symptoms (incontinence, gait disturbance and dementia) were present but currently, it may be diagnosed in the presence of just two or even one (30) to enable faster treatment.

- Constipation and diarrhoea: make it difficult for people with dementia to reach the toilet in time and to judge when it is necessary to go to the toilet. Bowel movements vary from one person to the next in terms of frequency and consistency. Constipation involves the passing of hard stools infrequently and with difficulty, bearing in mind what is normal for each person. The ageing process, lifestyle, having dementia and treatment for other medical conditions may contribute towards constipation (31). If left untreated, this may contribute towards faecal impaction. This involves the collection of hard stools in the rectum which prevents the person from passing stools naturally. This is further problematic when watery stools force their way past the blocked stool or secretion of glands in the rectum, resulting in overflow or seepage which may be mistaken for diarrhoea and can result in faecal leakage (31).

Nocturia typically involves people waking up from their sleep to go to the toilet to pass urine more than once at night. It is not a form of incontinence as it does not usually involve an involuntary loss of urine but it is nevertheless associated with continence problems and interferes with the ability to get a good night's sleep.

Wagg et al. (27) after reviewing several studies suggest that the prevalence of nocturia in older people is extremely high and increases with age. In people over the age of 80, for example, prevalence was as high as 90% for one episode per night. In people aged between 70 and 79, having two or more episodes per night, the prevalence was nearly 50%. In the under-60 age-group, more women than men experience nocturia and in the over-60 age-group more men than women experience it (32). In a study of patients with dementia, over 50% experienced nocturia more than twice per night and most people reported having to get up three times during the night to go to the toilet (33).

One reason for the increase in nocturia in older people is that they produce more urine at night (as a percentage of their 24-hour voided volume) than younger adults (34). They also have a higher prevalence of diabetes, hypertension (high blood pressure) and cardiovascular (heart) disease, all of which have been associated with nocturia. Although nocturia is not specifically linked to dementia, it may pose additional problems for people with dementia who may find it difficult to find the toilet at night in time and safely. This may in turn have an impact on carers who may also be woken from sleep multiple times to assist.

Some people are unable to empty their bladder (urinary retention) and need a catheter to evacuate their urine. This is linked to toileting and may be problematic to manage when the person also has dementia.

Given that some medical conditions can be treated and this can subsequently improve or resolve a person's incontinence, it is important to consider the impact of known conditions and their treatment during a continence assessment. This can sometimes be difficult to detect amongst people with dementia as they may have difficulty communicating their symptoms. For example, an elderly man with dementia might have bladder symptoms due to an enlarged prostate but this may go unrecognised unless properly assessed.

- > *Dementia is a progressive disorder with common symptoms but people are affected in different ways and do not all experience the same symptoms.*
- > *There are several types of urinary incontinence, as well as related medical conditions which influence ability to maintain continence.*
- > *People can have urinary incontinence or faecal incontinence or both (double).*
- > *People who might otherwise be incontinent are often able to maintain continence with appropriate support or aids or products.*
- > *Continence care for people with dementia living at home involves the provision of coordinated, long-term care by both professional and informal carers. This involves preventative measures, support and if necessary medical treatment and management.*

2.3 Facts and figures

The ageing population

The population of older people in Europe is steadily increasing. Life expectancy for women in Europe was 82.1 years in 2008 and it is estimated that it will increase to 89 years by 2060. The figures for men are 70 years and 84.5 years respectively (35). The number of people over the age of 80 is set to rise dramatically (36) and the number of centenarians has been steadily increasing since 1960 (37). It is estimated, for example, that in OECD (Organisation for Economic Co-operation and Development) countries the population aged over 80 will at least double, representing an increase from 4% to 10% of the total population (38).

Dementia

As age is the most significant risk factor for dementia (2), as the population ages, there will be a growing number of people with dementia. Younger people can also have dementia although this is less common (36; 14). It is important to avoid associating dementia uniquely with older people and overlooking the many younger people who also experience it.

Improving continence care for people with dementia living at home

There were an estimated 44.4 million people in the world living with dementia in 2013 and this figure is predicted to rise to 75.6 million by 2030 and to 135.5 million by 2050 (39). An estimated 8.7 million people in Europe (EU-28) have dementia (40) and the number of people with dementia in Western Europe is expected to double by 2040 (41; 42). There have been reports of underdiagnosis, with people with dementia not merely being diagnosed late, but not being diagnosed at all (43; 44; 45; 46). The number of people with dementia is likely to be much higher than current estimates might suggest.

Incontinence

Approximately 400 million people or 8% of the world population experience some type of urinary incontinence and these figures are likely to be an underestimate as many people do not seek help (3; 123). A review of numerous studies has demonstrated a correlation between increasing age and an increased prevalence of UI and suggests that age is an independent risk factor for UI (3).

“Older people have the highest known prevalence of urinary incontinence of any group, other than those with specific neurological disease e.g. spinal cord injury.” (p. 1003)

The high prevalence of incontinence amongst older people is likely to persist and may increase as the number of older people continues to grow at a proportionately faster rate than in the past. This is sometimes linked to the effect of the baby boomers reaching old age but also to general improvements in healthcare and older people being more active (47).

Estimates for faecal incontinence (FI) tend to be somewhat lower than those for UI. Wagg et al. (27) estimate that FI occurs in 2.2% to 25% of the general population, 9% to 30% of frail older adults, 18% to 33% of people in acute care settings and as much as 50% in the long-term care and institutionalised care settings. With regard to people living in the community, a Dutch survey-based study of 4,644 community dwelling people over the age of 60 (without dementia), 6% reported experiencing FI (48).

FI usually occurs alongside UI and its prevalence increases with age alone, particularly amongst people aged 80 and over (27).

Incontinence and dementia

Very few studies have investigated the prevalence of incontinence amongst people with dementia living at home. In a systematic review of UI and FI in people with cognitive impairment or dementia living at home, only 8 out of 850 records initially reviewed were about incontinence at home (11). These included studies involving people with dementia, those specifically diagnosed with dementia and those with cognitive impairment. The studies, which involved small populations of people with dementia, revealed a prevalence of UI

during the day of 34% (frequency not specified), 24% (frequency of once a day or more), 11% (once a week or more) and 11% (frequency of 3 to 6 times a week or more). In the same populations, the prevalence was between 21% and 34% for UI at night.

In the context of the same systematic review, three small-scale studies involving people with a diagnosis of dementia reported a prevalence of FI of 7%, 18% and 28% respectively. Aside from age, dementia is a primary risk factor for faecal incontinence (FI) (27). In a national general practice audit of 999 older patients with FI, 27% had a diagnosis of dementia (Wagg et al., 2005 in 49).

A comparison of estimates for incontinence amongst people with dementia living at home compared to those in residential care suggests that prevalence is higher for those in residential care. In a study based in Sweden, Hellström et al. (50), for example, found that 74% of people with dementia over the age of 85 living in residential care had UI compared to only 36% of those living at home. They also detected a gender difference in that 50% of the men with dementia compared to 60% of the women with dementia experienced UI (50). It must be considered that figures are likely to differ across Europe due to variability in healthcare systems and possibilities available for care at home. In addition, as incontinence is often one of the main reasons for institutionalization, availability of residential or nursing care homes may influence figures for individual countries.

In a study involving community-dwelling people with and without incontinence, those who were incontinent had more severe cognitive impairment than those who were continent (5). Milsom et al. (3) reviewed several studies into UI and cognitive impairment amongst women (including participants with confusion, lacking mental orientation as well as dementia). They suggest that there is a weak association between dementia and UI amongst community-dwelling women with mild dementia, but a moderate to strong association in the case of moderate to severe dementia.

There is insufficient information about the number of people with different forms of dementia who experience incontinence. The prevalence of UI amongst people with Alzheimer's disease ranges from 23% to 48% depending on the study (Burns, Jacoby and Levy, 1990; Cacabelos et al., 1996 – in 51). The degree of incontinence is associated with cognitive impairment and brain degeneration in that there is usually a correlation between its onset and the progression of Alzheimer's disease (18). However, this does not necessarily mean that increased incontinence is directly caused by increased brain damage as other factors must be taken into consideration.

Difficulties estimating the prevalence of dementia and incontinence at home

Relatively lower levels of incontinence have been reported amongst people with dementia living at home compared to those living in resi-

dential care (50) and reports of the prevalence of incontinence amongst the former vary considerably. There are four possible reasons for this.

1. People with dementia are generally admitted to a residential home when the level of functional and cognitive abilities is such that informal carers are unable to cope at home. Therefore, people with dementia at home may be better in terms of level of continence and cognition and this may also be the reason for the lower levels of incontinence reported amongst people with dementia living at home when compared to those living in residential care.
2. Cases of incontinence are likely to be under-reported and hence, the prevalence of incontinence underestimated. This may be due to the embarrassment, shame and perceived social stigma attached to both dementia and incontinence, combined with carers actively seeking to protect the dignity of the person experiencing incontinence (52; 26; 124). It is also possible that GPs do not record incontinence in the medical files of older patients due to the normalization of incontinence within this patient group. It has also been found that GPs who are less confident in their ability to treat incontinence tend not to discuss it with patients or arrange follow-up appointments (53).
3. Lack of agreement on definitions of what counts as incontinence (e.g. type and frequency of the problem), different inclusion and exclusion criteria for participants and different research methods (particularly one-off interviews) may all contribute to considerable variability in the estimations and calculations of the scale of incontinence amongst people with dementia living at home. Moreover, studies often rely on self-reported incontinence which may be more difficult for people with dementia (especially those living alone) due to cognitive or language difficulties.
4. Drennan et al. (11) suggest that some studies are too small to draw conclusions about the prevalence of dementia and incontinence, and that there is a need for validated tools to assess prevalence studies.

Worldwide, at least two thirds of people with dementia live at home (36; 54; 12). However, figures vary greatly between countries and between urban and rural areas within the same country. For example, in Greece, 80-89% of people with dementia in urban areas live at home, compared to 95-99% in rural areas, whereas in Sweden 50-59% of people with dementia in both urban and rural areas live at home².

The number of people living with dementia is increasing and many governments are striving to enable people with dementia to continue living in their own homes. It is therefore essential to ensure that those who experience incontinence receive appropriate and good quality care and support. In many cases, this will also involve the provision of support to informal carers, who are also affected by the incontinence of the person with dementia. It is important for such planning to be able to estimate effectively the scale of continence problems amongst people with dementia living at home.

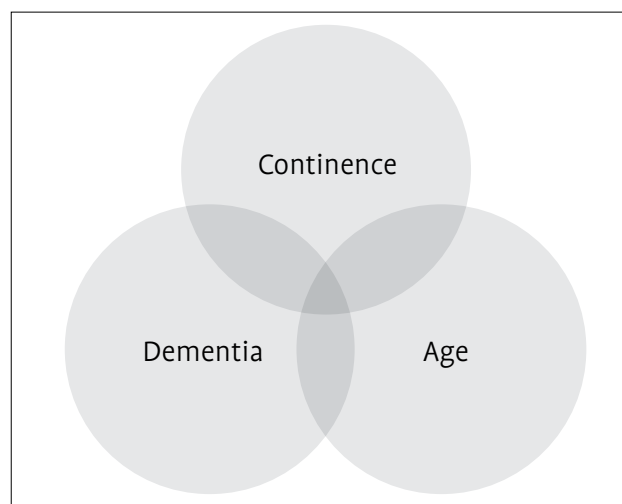
- > *The prevalence of dementia and incontinence is increasing.*
- > *The number of people with dementia living at home, who may at some point experience continence problems, is increasing.*

> *More research is needed into the prevalence of incontinence and the scale of continence problems experienced by people with dementia living at home.*

2.4 The intersection of dementia, continence problems and age

In focusing on improving continence care for people with dementia at home, we must consider three key factors, namely continence, dementia and age, and in particular, the complex relationships within the intersections particularly in the context of people's own home/community (see Figure 2 below).

Figure 2: The intersection of continence, dementia and age



Some prevalence aspects of ageing and incontinence, ageing and dementia and the relationship between dementia and continence problems have been discussed. It is also important to consider certain physiological and biological interactions between continence problems, dementia and age, as well as issues related to memory, understanding and communication.

2.4.1 Ageing

The physiology of ageing is complex and well documented. However, in most cases it is difficult to distinguish between age-related changes and signs and symptoms association with age-related conditions. The changes that happen as one ages include:

Brain changes: The effects of ageing on the brain and cognition are widespread and have multiple aetiologies (causes). Ageing has its effects on molecules, cells, blood vessels, gross morphology and cognition. As we age our brains shrink in volume. As our blood vessels age and our blood pressure rises, the possibility of stroke and lack of blood supply to areas increases the development of white matter lesions (areas of damage). Some degree of memory decline

² Results from an unpublished ADI survey – see reference 54.

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also occurs with ageing although this does not mean that dementia is a natural consequence of ageing. Genetics, neurotransmitters, hormones, and experience all have a part to play in brain ageing.

Bladder changes: Changes to nerves, muscles and hormones result in:

- reduced bladder capacity,
- a lesser sensation in the bladder making one less aware of the need to pass urine,
- an increase in uninhibited contractions of the bladder muscle (detrusor) manifesting detrusor overactivity (involuntary contractions), impaired contractility (difficulties contracting the muscle), or a combination of both,
- decreased urinary flow rate,
- diminished urethral pressure profile (a record of resistance of the urethra to the flow of urine) (particularly in women),
- increased post-void residual urine volume (leaving urine in the bladder),
- increased night-time production of urine,
- an increase in men having an enlarged prostate gland and prostate cancer which can affect urinary symptoms.

Muscle changes: Sarcopenia is the degenerative loss of skeletal muscle mass quality, and strength associated with ageing. This has an effect on mobility and functionality resulting in physical decline (55).

Increased risk of disease: Multiple comorbidity, is common and greatly increases the complexity of managing disease. In developed nations, about one in four adults has at least two chronic conditions and more than half of older adults have three or more chronic conditions (56). Some of the chronic conditions have already been mentioned in 2.2.2.

Increased risk of being on several medications: Polypharmacy is the term used to describe the consumption of a large number of prescribed tablets on a regular basis. Studies have shown that people over the age of 65 in the US, UK and Canada, whilst making up 12-16% of the population, consume 32%, 50% and 45% of prescribed medication, respectively (27). Amongst the over-65 age group, about 60% take at least one prescribed medication and about one third take more than five, with the risk of adverse drug reactions increasing as the number of prescribed drugs increases (27). Numerous well documented potentially inappropriate medications are used in older adults even though there is clear evidence that these drugs may be ineffective if not harmful.

Sometimes, a drug is given to address a problem which is actually a side effect of another drug. If a review of medication is not carried out, yet another drug is added to the list, thus increasing the risk of further adverse drug effects, when the withdrawal of the first drug might have solved the problem.

For example, a side effect of certain blood pressure tablets is ankle swelling. A doctor may prescribe water tablets to get rid of the ankle swelling whereas the simplest thing may have been to try a different blood pressure tablet. Age-related changes also affect the way that drugs are absorbed and distributed in the body, as well as a person's

metabolism and the clearance of the drugs from the body. This is important as in certain circumstances lower doses of drugs are advisable or indeed occasionally higher doses.

2.4.2 Dementia and continence problems

A person with dementia is more likely to have "accidents", problems with the toilet or incontinence than a person of the same age without dementia. There are many reasons such as:

- "not being able to react quickly enough to the sensation of needing to use the toilet,
- failure to get to the toilet in time, sometimes due to mobility problems caused by other conditions,
- not being able to communicate the need to go to the toilet,
- inability to find, recognise, or use the toilet; if someone becomes confused about their surroundings, they may urinate in an inappropriate place (such as a wastepaper basket) because they have mistaken it for a toilet,
- not understanding a prompt from someone to use the toilet,
- not managing the personal activities of toileting, such as undoing clothing and personal hygiene,
- not letting others help with toileting, perhaps because of embarrassment or not understanding the offer of help,
- not making any attempt to find the toilet; this could be due to lack of motivation or depression, or because the person is distracted,
- embarrassment after an accident, which the person unsuccessfully tries to deal with. Wet or soiled clothes or faeces may be put out of sight (for example, wrapped up and put at the back of a drawer) to be dealt with later, but then forgotten." (57)

2.4.3 Drugs for dementia, continence problems and possible interactions

Drugs prescribed for Alzheimer's disease (e.g. cholinesterase inhibitors such as galantamine, rivastigmine and donepezil) can cause or worsen incontinence and anti-muscarinics which are the main type of drugs used to treat urinary incontinence (e.g. oxybutynin) have been shown to impact on cognitive impairment (58; 59; 60; 61). Moreover, the interaction between these types of drugs can potentially influence their effectiveness. Consequently, such drugs may be used but with caution due to the effects of their interaction and possible side effects. Continued use of anti-cholinergic medication over a four-year period appears, in addition, to be associated with cognitive impairment and an increased risk of dementia (58). Many clinicians are therefore wary of prescribing medications for UI in older patients but even more so for people with a diagnosis of dementia.

The newer anti-muscarinics for OAB and UUI (e.g. Darifenacin, Fesoterodine, Solifenacin, Tolterodine and Trospium) do not appear to adversely affect cognition but there is very little data on their use in people with a diagnosis of dementia. There is a newer drug on the market which does not have any known effect on cognition called Mirabegron (a "beta-3

agonist”) which may be an option for people with dementia but again there have not been sufficient trials conducted involving people with dementia.

Many other general medications can impact on continence and cognition and therefore it is very important to ensure a good medication review and remove any unnecessary medications.

Despite certain physiological changes and medical problems or diseases, which are more common in older people, incontinence should not be considered an inevitable part of ageing (3). Similarly, the possibility of a younger person with dementia or of a person with mild dementia having incontinence should not be overlooked.

Neither dementia nor incontinence is a purely physical/biomedical phenomenon. Consequently, it should not be assumed that UI is linked solely to the bladder or that continence problems in the case of a person with dementia are due solely to brain damage. Such an assumption would reflect a narrow biomedical approach, which reduces the whole person with dementia to a mere brain and a person with continence problems to his/her bladder or bowels. Both have social, cultural, emotional and psychological elements, which have an impact on physical and mental health, wellbeing, independence, relationships and social inclusion (this reflects what is sometimes called a biopsychosocial approach).

Dementia and incontinence can be part of a syndrome called frailty. With frailty, there can also be muscle weakness and problems with endurance, balance and nutrition. Extra caution is needed and these problems must be addressed when treating older people with frailty.

> *Dementia, continence problems and ageing have complex interactions. It is important to understand those interactions in order to consider management options for people in their own homes/ community.*

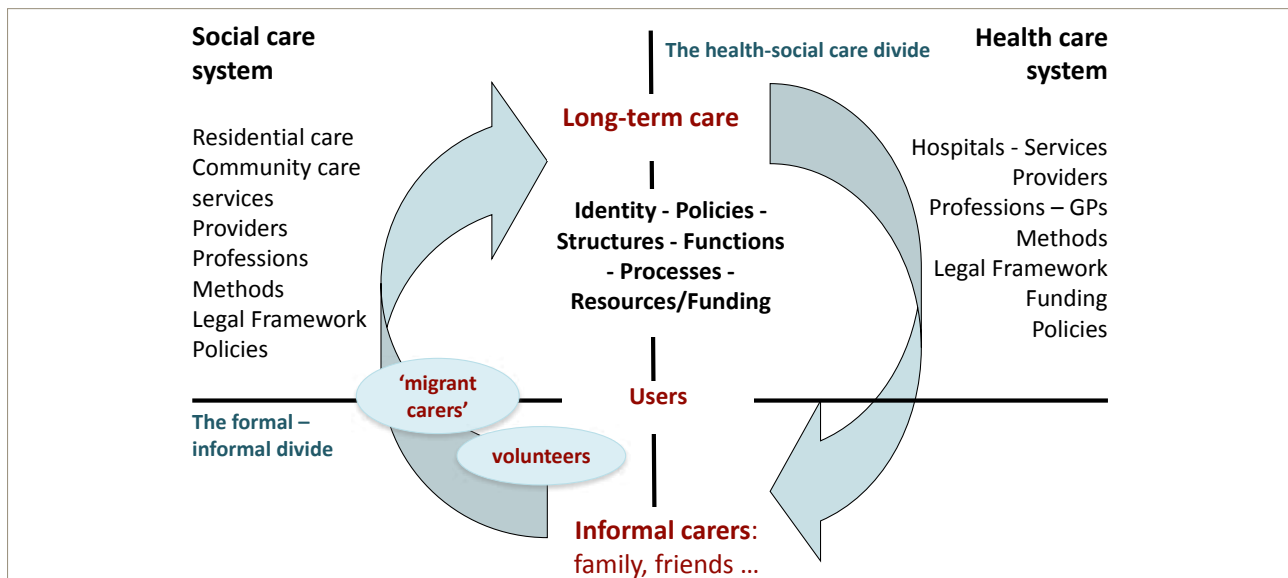
> *A biopsychosocial approach is more appropriate than a biomedical approach in understanding how dementia and incontinence impact the person with dementia and their family.*

2.5 Continence and dementia care as part of the long-term care process

Dementia and incontinence are typical examples of conditions with complex care needs that require a number of interventions spanning the continuum between social and health care as well as between formal and informal care (62). However, the provision of adequate long-term continence and dementia care is dependent on an integrated long-term care system with well-designed policies, structures, processes, functions and resources, regardless of where the care is provided.

In the home setting, informal carers, such as spouses, adult children and other relatives or close friends, provide the vast majority of the care needed. Formal support, care and treatment is provided or organised through the social care system and/or the healthcare system, to different degrees. This will vary according to individual countries, and may also be affected by lack of resources, different funding systems or lack of communication between stakeholders in the different sectors. Figure 3 shows how an integrated long-term care system is positioned and linked to social and health care systems, as well as the crucial role of informal carers (63).

Figure 3: Positioning integrated long-term care between health and social care systems. Source: <http://interlinks.euro.centre.org/>



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The term “carer” (or “caregiver” or “informal carer”) might be considered as implying a relationship of dependency which results in people with long-term care needs (e.g. with dementia and incontinence) being positioned as recipients of care. However, people with dementia have varying levels of autonomy and dependency on others at various stages of the disease. The term “carer” is often used to denote people who provide long-term care on an unpaid basis. Usually, they are relatives, partners or close friends. Some do not even consider themselves as “carers” or do not feel that they provide care. In particular, carers of people with dementia often feel that they provide more care than they would like to provide, have no training, are not formally recognised and were more or less forced into the role of carer (64).

The term can also be interpreted as recognition of the fact that not all relatives are carers and vice versa. The concept of “informal carer” is further blurred by the increasing number of live-in personal assistants, often with a migration background, who provide care for older people in many countries on a private basis, with minimum payment and often no formal training (65; 66). These “migrant carers” are, however, an important resource for families and should also be considered as crucial reference persons for healthcare professionals who are assessing and treating people with dementia and continence problems.

> Dementia and continence problems are complex issues triggering long-term care needs that have to be addressed by health and social care professionals in cooperation with informal carers.



3 Living with dementia and continence problems at home

3.1 How incontinence is perceived within society

Social norms, expectations and stigma

Public perceptions of dementia and incontinence vary. A small study into how people with dementia perceive dementia revealed, for example, that perceptions ranged from “no big deal” to “hellish” (67). However, older people and carers often consider urinary incontinence amongst older people as inevitable, irreversible, part of normal ageing and a sign of incompetence (68). There are cultural expectations for adults to effectively control when and where elimination takes place. It tends to be assumed that this should be done privately and that signs of leakage should be concealed. Whilst there are cultural and historical variations in the age at which infants are expected to achieve independent toileting, the acquisition of toileting skills has been described as a nearly universal developmental milestone (69). These cultural expectations and related fears are exacerbated in the case of dementia which is also often incorrectly attributed to normal ageing, which typically involves a gradual loss of capacities and sometimes the infantilisation of people with dementia (70).

Incontinence has been described as “the last medical taboo” (71) and when combined with dementia as a double stigma in that each is often considered independently as a stigma. Drennan et al. (52) describe this as “the taboo of incontinence inside the stigma of dementia”. They found that carers were reluctant to seek help for continence problems, as they were concerned about the dignity and personhood of the person with dementia.

Stigma is a complex social phenomenon involving public and private processes in which groups of people sharing a socially salient characteristic/attribute (e.g. dementia and/or continence problems) are devalued and discriminated against, either overtly or covertly (72; 73). The perceived stigmatising attitudes of others may be internalized and discrimination either experienced or anticipated (74; 75). The term “stigma” is also used to refer to the attribute itself which is deeply discrediting in that it reduces someone in other people’s minds from a “whole and usual person to a tainted, discounted one” (76, p. 12). According to Jones et al. (77), certain factors increase the likelihood of a particular attribute leading to stigma. The following bullet points list the contributing factors and suggest how they might apply to continence problems.

- concealability (whether continence problems are visible or can be hidden),
- aesthetics (whether a person is considered as “repellent, ugly or upsetting” due to continence problems),
- the course of the mark (whether continence problems are perceived

- as becoming progressively worse or more debilitating),
- peril (whether continence problems are perceived as a threat to physical, psychological and social well-being),
- disruptiveness (whether continence problems “hinder, strain and add to the difficulty of interpersonal relationships”),
- origin (whether a person is considered responsible for having continence problems).

It is not the attribute itself that is stigmatising but the meanings attached to it. Such meanings are socially constructed and hence have the potential to be changed. The belief or awareness that dementia is perceived as a stigma may make people reluctant to seek diagnosis and result in GPs being hesitant to broach the topic (78; 79; 80). Vernooij-Dassen et al. (80) state,

“The hesitancy and delay surrounding timely recognition is prominent in all EU states and specialist services in themselves are not enough to overcome this. Stigma associated with dementia by professionals seems to be the most powerful influential factor.” (80, p. 384)

Patients’ presumed discomfort surrounding discussions about incontinence may also lead to hesitancy by healthcare professionals to address this issue and interfere with people with dementia and incontinence receiving good incontinence care at home. According to Milsom (81),

“There is little doubt that the unfashionable and taboo nature of incontinence is a barrier that prevents effective discussion and practical intervention.” (81; comment made during 2nd Global Forum for Incontinence, Nice France)

The combination of these two very stigmatising conditions may lead to oversights and omissions in integrating services linked to mental and physical wellbeing (49).

Stereotyping, normalisation and a “return to childhood”

The presumption that a person is unable to make decisions because they have dementia reflects a stereotype. It is a generalisation which is not based on an individual assessment of capacity. As mentioned in section 2.2.1 on dementia, capacity is task specific and should be assessed in relation to each decision that needs to be made. Such stereotyping could contribute towards the assumption that people with dementia are unsuitable for certain forms of continence care (e.g. as they are unable to follow instructions).

It is sometimes presumed that people with dementia have little or no quality of life. Carers sometimes perceive the quality of life of people with dementia as being lower than people with dementia do themselves (82; 83; 84). Stereotypes about people with dementia and/or continence problems having no quality of life are dangerous.

They may influence healthcare professionals' perceptions of the potential benefits of assessment and referral in relation to various continence care options for people with dementia.

The stereotyping of older people tends to highlight physical and cognitive decline, dependency, loss of autonomy and interpersonal deficiencies (85; 86). This blurs the distinction between ageing and dementia and may contribute towards normalisation (i.e. attributing signs of dementia to normal ageing) (87; 88) and to the belief that nothing can be done. References to cognitive decline as an inevitable part of ageing and even as a "return to childhood" can be found in literature and the arts dating back over a thousand years (89; 90). More recently, some healthcare professionals have linked this perception to theories of child development. Barry Reisberg, for example, described different stages of Alzheimer's disease and linked them to the stages of infant development but in reverse order (e.g. the control of bowels and urine being acquired at around 2-3 years and 3-4½ years respectively for children and lost in stage 6 of Alzheimer's disease) (90). Cayton (90) argues that the underlying processes are totally different. The perception of a return to childhood fails to recognise the dignity and adult status of people with dementia and over-emphasises the biomedical aspects of dementia and continence problems.

3.2 Challenges linked to the continence care of people with dementia at home

Lack of knowledge and training

A lack of knowledge and appropriate training of healthcare professionals, especially GPs, has been reported in relation to incontinence. In a Canadian survey amongst GPs, for example, it was found that less than half felt that they had a clear understanding of incontinence and in a UK-based study, only 32% of GPs were aware of at least one investigation for incontinence and/or one form of surgical treatment (Szoni and Muillard, 1994 and Thekkinkattil, 2006 in 27). According to the British Geriatric Society (2007), health professionals' initial response to incontinence amongst older people is often to provide continence pads only rather than to assess and treat underlying causes (49).

Many GPs lack knowledge about community services and resources and find it difficult to diagnose dementia or to distinguish between dementia and normal ageing (91). Whilst some are more confident about their ability to diagnose dementia (92; 93), some would nevertheless appreciate more training (94).

The knowledge and training of lay people and carers is vitally important for the management of dementia and continence problems in the community. Awareness about and management of continence problems have been found to be lacking amongst lay people, especially amongst men, those aged 85 and over and those with a lower

level of education (Branch, 1994 in 27). Some may therefore tend to rely solely on containment products (e.g. pads) and be unaware of other ways to manage continence problems.

Poor support offered to people with dementia and carers living at home

The level and quality of support offered to people with dementia and continence problems varies considerably from one country to the next and even within countries. Some people have access to specialist nurses, continence advisors/nurses or a continence advisory service and receive information, psychological support, advice about possible environmental changes and discussions about the best possible continence pad solutions, treatments and other interventions. Others only have access to information from their GP or other health and social care professionals, many of whom lack specialised knowledge about the combination of dementia and incontinence. There is a wide range of different containment products, especially incontinence absorbing pads/pants and protective underwear available to manage the individual needs of people with dementia and continence problems living at home and to meet the needs of their carers. Continence pads differ in absorption level, odour control, skin friendly, breathable material and ease of handling. Individual fitting to the person and their situation is crucial.

Carers who seek advice from their GP sometimes feel that it is not helpful because it is either too brief or does not take into account their situation or dementia. In one study, carers reported that some healthcare professionals were helpful but that most did not provide appropriate help and advice and merely passed them onto another professional who was equally unhelpful (52). Carers suggest that healthcare professionals would benefit from a better understanding of the issues related to the continence care of people with dementia home (52; 95).

The supply and use of products for continence care

People with dementia and continence problems may face challenges linked to the organisation and use of various products for continence care, especially if they live alone or are trying to manage on their own. It is necessary to plan ahead, calculate the number of products needed, understand delivery procedures, place and receive orders and store products in a convenient place, all of which requires cognitive skills. In addition, they need to be aware of their changing needs.

Products for continence care have a particular practical or physical function but their use also has social and psychological implications (96). Commodes and bedpans, for example, are not always useful because people are reluctant to use them or do not understand their purpose. Some people with dementia do not realise that a commode is a toilet or consider it unacceptable to have it anywhere other than in the bathroom (52). Professional carers may sometimes be insen-

Improving continence care for people with dementia living at home

sitive to people's feelings about the use of continence care products in the home. Failure to consider how they are perceived by potential users may result in them not being used and consequently, in people with dementia and carers lacking support.

Mobility and the environment

As mentioned in section 2.4, people with dementia may fail to reach the toilet in time and have accidents simply because they are not sufficiently mobile and not because they are actually incontinent (97). Certain symptoms, experienced by people with dementia, such as disturbed gait, lack of coordination and jerky movements, may interfere with mobility (98). This can make it difficult for people with dementia to reach the toilet in time and may put them at risk of falls or of hesitancy to make their way to the toilet unassisted.

People with dementia are sometimes physically and chemically restrained and thus prevented from moving about freely. Apart from this being unethical and in many cases illegal (99), this deprives them of the opportunity to get to the toilet in time and may result in them becoming incontinent. The reported use of physical restraint in nursing homes varies from 4% to 85% (111) but the extent of the problem in people's own homes has not been adequately documented. The over-use and inappropriate use of anti-psychotics for people with dementia in nursing homes and at home have been reported (100). There have been concerns about the known risks associated with some of these drugs for people with dementia and their use as a form of restraint (99; 100).

Mobility problems may be exacerbated by the layout or structure of the home (e.g. on one floor or with different levels, with a separate toilet or one in a bathroom, open plan or several rooms off a hallway, uneven floors and poor lighting) and the furniture in it (e.g. furniture blocking the way, low furniture with sharp edges, chairs which are difficult to get up from, heavy doors and mirrors and identical doors throughout). It may be difficult for carers to provide assistance if the toilet (i.e. the room) is not big enough for two people. Most people's homes were not designed with the needs of people with dementia and continence problems in mind and although home adaptations may be possible, they are not necessarily considered feasible or desirable.

For people with dementia, difficulty getting to the toilet in time may also be linked to memory problems, the inability to judge accurately distance, height (of steps on staircases) and motion or difficulties working out how to get from where they are to the toilet. Dark patches may be perceived as steps or holes, the person's image in a bathroom mirror may result in them thinking that it is already occupied. Even when people with dementia manage to reach the toilet in time, they may have difficulty recognising it by visual means alone or mistake other objects for it. Other problems with vision include difficulty aiming into the toilet (for men) as the toilet does not

stand out sufficiently from the surroundings (e.g. white toilet and toilet seat on a pale tiled floor).

In the residential care setting, the labelling of toilet doors with an image and the word "toilet" combined with way-finding arrows on the floor, as well as various measures to make the toilet highly visible, have been found to have a positive effect on managing continence (101). Measures must be suited to the individual and some may be more readily accepted in formal care settings than in people's own homes. Sometimes, people with dementia consider certain measures, such as signs on walls and doors, inappropriate in their home (52).

Availability and accessibility of public toilets

It is sometimes assumed that the lives of people with dementia are "home-based" (102). However, people with dementia and continence problems do go out, and when they do, they need access to public toilets which are suited to their needs. Public toilets are often only open at certain times of the day, are insufficient in number and not well signed. Some require coins to open the door or to pass through a barrier/turnstile. Some have electronic locking mechanisms with symbols and novel flushing mechanisms which could be confusing for people with dementia. Relying on access to public toilets requires the ability to find them (perhaps asking and following directions), to understand abstract signs and manage barriers and doors and some degree of luck (i.e. that they are open). It may be difficult for carers to provide assistance if the public toilet is just for one sex or if there is not enough room for two people to enter into the cubicle.

People with dementia who use continence pads need somewhere to put the soiled pads. Women usually have access to sanitary disposal bins in public toilets. Bins can also be found in some public toilets for disabled people but people with dementia and continence problems do not necessarily consider themselves as disabled. It may therefore be more difficult for men to manage their continence problems discreetly when not at home.

Diomedes et al. (71) describe the lack of suitable public toilets for people with continence problems as a social and architectural barrier to freedom of movement and to all intents and purposes as placing people "under house arrest". Failure to provide suitable toilets which are accessible to people with dementia and continence problems (and their carers if assistance is needed) is an example of failure to provide "reasonable accommodation" in accordance with the United Nations Convention on the Rights of Persons with Disabilities (21).

Maintaining a fresh and clean home environment

It can be stressful and hard work trying to maintain a fresh and clean home when someone with dementia has continence problems. People with dementia and carers may worry about what visitors will

think, what they might say to other people and whether they will stop visiting. Indeed, the smell of faeces and urine can be disturbing even though some people with dementia sometimes seem to be unaware of the smell (103; 95).

There are some products on the market to mask the smell of stale urine and absorb the smell of flatus. Fabrics have been designed for chairs, clothes and bed linen which have been treated with anti-microbial agents and there are products to treat urine spillage which destroy the bacteria responsible for the breakdown of urea (which otherwise can lead to the pungent smelling ammonia). According to Cottenden et al. (104), there is a lack of robust evidence as to their efficacy of these products but anecdotal evidence that they are useful to some people.

Constant vigilance and round-the clock caring

Some carers get up once or more often at night to change the continence pad, sheets or nightwear of the person with dementia or to take him/her to the toilet. Unlike professional carers who work nights and can sleep afterwards, carers often cannot and this may take a toll on their health and wellbeing (124).

This may sometimes seem like a never-ending process of changing pads, putting dirty washing in the laundry basket and loading and unloading washing machines. Some carers feel a constant tension based on the perceived need to be vigilant and to try to predict and prevent accidents.

“You’re actually just waiting for it to happen again, so that you’ll have to freshen him up again... You’re waiting. It’s almost as if you could prevent it from happening, be quicker, be attentive so that it doesn’t happen in the first place... And there’s a feeling that you’ll never be free from it, not for the whole year... And it makes you so tense inside.” (95, p. 18 – our translation)

Managing toileting procedures

Using the toilet successfully involves being able to undo, lower, raise and replace clothing, get on and off the toilet and remain there for as long as necessary. This may be hampered by lack of dexterity, other health conditions (e.g. arthritis and tremors) and a decreased attention span (105). People with dementia may also have difficulties planning and carrying out actions involving different steps and in recognising objects such as the toilet. In addition, men need to be able to “aim” when urinating and men and women need to clean themselves after having gone to the toilet. Such difficulties may go unnoticed for some time amongst people with dementia living at home and when not successfully accomplished, carers may mistakenly believe that the person with dementia is incontinent (e.g. due to soiled clothing, urine on the floor and poor hygiene).

Resisting assistance with toileting

Some people with dementia may be uncooperative and resist carers’ attempts to assist with toileting (106). This might involve disruptive or aggressive behaviour (107) or the person with dementia asking to be left alone.

Several reasons for this are possible. For example, the person with dementia may feel embarrassed about a member of his/her family helping with such intimate care. Some people may feel humiliated and associate the need for assistance with a loss of dignity and of adult status. Aphasia (a disruption of the ability to comprehend and to communicate) may also contribute towards resistance to care. The person with dementia may fail to understand a carer’s attempt to provide assistance and even interpret such attempts as indecent assault, particularly if they do not recognise the carer. Aphasia may lead to anxiety and result in the person with dementia communicating as best they can, which in turn may be interpreted by carers as “challenging behaviour” (105). The following quote is from a daughter caring for her mother with dementia.

“The problem is she doesn’t like people touching her. She knows she wants to go to the toilet, you get her there, then she doesn’t want to pull her trousers down so you have to start, you have to do it, so she’s going to fight...If she gets your fingers, she’ll try and break them.” (52, p. 4)

Resistance may result in the person with dementia remaining soiled with the risk of infection. It may also contribute towards decisions to institutionalize the person with dementia.

The inappropriate voiding and handling of faeces

A study into the management of incontinence amongst people with dementia living at home described a range of problems typically encountered by carers (52). This included the person with dementia voiding in inappropriate places such as in the garden, beside the bed at night or in waste bins. Carers also described people with dementia attempting to hand faeces to them and wiping faeces off their hands onto clothing and furniture. This is not limited to incontinence but to toileting in general. Faeces or urine may also be displaced (e.g. onto the floor, seats, walls, clothing or hands), particularly when the person with dementia resists help from carers.

Such difficulties, if not detected rapidly, may lead to unpleasant smells and infection and can be emotionally disturbing for carers (see section on the emotional impact of incontinence). However, carers sometimes feel embarrassed or reluctant to seek advice due to the intimate nature of the problem and concerns about protecting the dignity of the person with dementia. They may also feel that they have no one to turn to for assistance but it is impor-

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tant that they inform a health or social care professional about the problem.

The cost of providing care at home

Providing continence care at home can be costly and has been described by some carers as the most expensive aspect of care (95). The most obvious cost is that of continence pads but there are also costs linked to washing clothes and sheets, detergent, electricity, transport to the launderette and using public washing machines. There may also be costs linked to cleaning floors, furniture and the toilet area and even replacing carpets and armchairs.

Caring may also result in a loss of time and hence a cost as that time could have been spent either in paid employment or in the pursuit of leisure activities (108). There may also be indirect costs linked to the loss of pension rights or a reduced pension. The cost of continence and dementia care also depends on which costs are covered by the government and whether there are any schemes to facilitate flexible working hours to help people to combine more effectively paid employment and caring.

3.3 The impact of continence problems on relationships

The involvement of relatives and friends in the provision of continence care

Irrespective of their willingness and desire to help, carers may sometimes feel quasi obliged to provide assistance due to social expectations (particularly for women) or the way that formal care is organised (e.g. a lack of formal services or eligibility criteria). However, lack of training and the nature of their relationship to the person with dementia may make this difficult for them but also for the person with dementia.

The perceived appropriateness of a family member helping a person with dementia to provide continence care is likely to differ from one family to the next. In some families, gender may be an issue in that there are differences of opinion as to whether sons should assist their mothers and some husbands/male partners are reluctant to provide such assistance (52). This may be due to different cultural expectations about gender roles but also reflect individual differences based on the unique nature of relationships and familial ties. Nevertheless, situations arise where there is little choice and the availability of services and socio-economic factors clearly influence this issue.

Relationships involve different levels of intimacy. Some carers may find it difficult if not impossible to cross certain boundaries linked to voiding (e.g. involving exposure, touch and hygiene) and people with dementia, like anyone else, have varying degrees

of comfort with being touched and varying degrees of desire for privacy. If carers feel obliged to provide assistance, this may be distressing for the person with dementia and the carer.

Role reversal and infantilisation

It might be considered acceptable for a professional carer to ask about bowel movements and prompt a patient or resident to go to the toilet but perhaps less so for a friend or relative to do likewise. Some carers have reported this leading to people with dementia being irritated and to arguments, as they feel that they are being infantilised (52).

Carers often perceive a reversal of roles in their relationship with the person with dementia.

“It’s funny I guess, children and their parents, their roles kind of totally change. Children have their own families and become parents and then become parents almost of their parents. (109, p. 343)

Providing continence care may be one factor contributing towards this overall impression. However, even though infants take time to master continence and some people with dementia may have difficulties with continence, the latter are not and do not become children. Considering and treating a person with dementia as a child affects the nature of relationships between people, touching for example on recognised adult status, power relations and the social roles that people occupy as a spouse, lover, parent, friend and grandparent, etc.

Spouses and partners may find it difficult to be attracted to the person with dementia and to engage in a sexual relationship due to changes in character and behaviour linked to dementia but also to the provision of intimate personal care and persisting problems with continence. The situation is different in nursing homes because health and social care professionals provide such care and they have no personal relationship to the person with dementia.

3.4 The emotional impact of continence problems

Different and changing reactions to continence problems

Dementia and continence problems can both be perceived and experienced in many different ways. Some people approach life with dementia and/or continence problems with a positive attitude, aiming to get on with their lives as best they can, making use of available support and/or focusing on what is still possible. Some people with dementia emphasise that they are “living with dementia” and not “suffering from dementia”. Others react with resignation, fear or shame. Experiences and attitudes may change

as life progresses, as each condition develops and as different situations arise. It is therefore important to be attentive to the feelings of people with dementia and continence problems and to avoid making assumptions about how they feel, especially as they may have difficulty communicating their feeling.

Dealing with disgust, revulsion and despair

Carers have described feelings of distaste and contamination linked to the task of attending to the hygiene of people with dementia, especially after defecation (52) and of disgust/revulsion linked to seeing used continence pads, having direct contact with excrement during continence care and in relation to their partner (95).

This can lead to carers feeling overwhelmed and emotionally disturbed. Some carers do not feel fully understood by healthcare professionals, some of whom have a limited understanding of the problem, seeing it merely as consisting of concerns about hygiene (52, p. 4). Carers sometimes feel that healthcare professional focus on technical details and provide tips on coping but just take it for granted that they will provide continence care. The whole issue of how they feel about it or are affected by it is not addressed (95).

Feelings of humiliation and loss of control

When providing direct continence care for a person with dementia, some carers feel that they are doing something that is dirty or rude/improper and feel humiliated, degraded and disheartened, especially when disputes and clashes occur during continence care (95).

“I have never felt so humiliated...You can hardly sink any lower than being on your hands and knees and having to clean up someone else’s shit. It’s so degrading.” (95, p. 16)

Some feel that they are at the mercy of incontinence and have lost control over their own lives. Incontinence may arouse fears linked to the progression of the disease as it symbolises and brings home to carers the progressively worsening condition of the person with dementia. Some carers feel guilty and disappointed about their difficulties coping but also for having considered the person with dementia moving into a residential care home (95).

3.5 Ethical issues and dilemmas

Ethical behaviour in relation to caring for a person with dementia is more than a question of rights and duties and cannot be equated merely with respecting laws or abiding by culturally determined norms, religious teachings, science or social conventions (126). There are several ethical theories about what should be considered as “good” or the “right” course of action to take. For example, there are utilitarian, consequentialist, fairness, virtue, rights-based, feminist and common good approaches. There is also a principlist approach

which focuses on biomedical ethical principles. These include respect for autonomy (being independent, able to decide what should happen or be done to you), beneficence and non-maleficence (acting to benefit and promote the good of the other person whilst avoiding doing them any harm) and justice (treating people equally and fairly) (110). However, in view of the complexity of human relationships and of people’s lived experience, doubt has been expressed about adopting an approach which focuses solely on these principles.

Gastmans (1) has proposed an ethical framework for dignity-enhancing care which focuses on the lived experiences of people with dementia and their carers in relation to care giving, care receiving, vulnerability and dignity. In this context, he also emphasises a range of related principles and values such as integrity, humility, privacy, historicity (elements of a person’s past and experience which have made them who they are) and singularity (what makes every person a unique individual), as well as the importance of relationships. People with dementia are vulnerable with regard to the psychological, relational, social, moral and spiritual dimensions of their being human, regardless of whether they are cognitively aware of their vulnerability. This may threaten their dignity (as they are not in a position to force respectful behaviour and attitudes from others) and lead to dependence on others (1).

Ethical dilemmas occur in situations in which moral principles or values are in conflict and where it is difficult to interpret or decide what would be the right or wrong course of action or attitude to take (112). The right thing to do in response to an ethical dilemma will often be to “treat a person as a person” (113). However, it is not just about one person. Whilst it is important to put the person with dementia at the centre of care and care decisions, it would be unethical to disregard the needs, wishes and rights of carers (e.g. in relation to support, dignity, privacy and justice). The following sub-sections provide a few examples in relation to the experience of continence care and emphasise the need to discuss issues with all concerned, to take time to interpret what is important and meaningful to each in the context of their lives, values, the situation and their relationship to others (1).

Dignity

Sometimes, carers try to hide continence problems from outsiders in order to protect the dignity of the person with dementia (e.g. disposing of soiled pads at night to avoid neighbours knowing and trying to manage alone without seeking help) (52). Whilst this is understandable, it prevents other people from offering support and may lead to over-protection and failure to consider current values and wishes. Ostaszkiwicz (114) highlights taken-for-granted values and expectations about cleanliness, uncleanliness and the social stigma of incontinence as well as the tendency to associate cleanliness with a state of dignity.

Dignity can also be affected by the manner in which care is provided and by whom. The use of continence pads, for example, may

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contribute towards self-esteem by providing a sense of security, of being taken care of and of being in control, especially when a person can perform or contribute towards their own continence care (115). On the other hand, some people feel like babies and are embarrassed about receiving such intimate care and about their ageing bodies (115). People with dementia sometimes seem unconcerned about being in situations which they would have previously considered undignified. Some may be simply unable to communicate their feelings.

Privacy

People with dementia desire different levels of privacy regarding continence problems. Some are comfortable talking openly about them, whereas others would find that embarrassing, even or especially with their relatives and friends. The same applies to carers but the needs of people with dementia and carers may differ in this regard. This may lead to levels of secrecy or openness that are inappropriate, unhelpful and even disturbing to those concerned. It is therefore important to challenge the stigma of incontinence but also to find the right level of openness and discretion required by individual people with dementia and their carers.

Respecting autonomy and dignity whilst preventing harm

People with dementia have a right to autonomy, independence and self-determination. This may sometimes involve them refusing or resisting assistance. Such refusal or resistance may be due

to a misinterpretation of carers' intentions or a form of communication itself perhaps linked to other issues such as frustration, anger or embarrassment. It may also be a clear expression of their wishes, namely to be left alone and not be assisted. The consequences may include the person with dementia sitting around in soiled pads or underwear for lengthy periods, smelling unpleasant, risking falls whilst making their way to the toilet, having damaged skin and being perceived as dirty and undignified.

Carers may wish to respect the autonomy of the person with dementia but feel responsible for protecting their dignity, health and wellbeing. This represents the same kind of competing duty of care experienced by many professional carers, consisting of a desire to respect autonomy, keep the person safe and address physical care needs (114). Carers may also have fears that failing to intervene would amount to the neglect of a vulnerable person.

Such concerns sometimes result in the use of force and thus failing to respect the person's autonomy and ironically, their dignity, as well as causing emotional, psychological and physical harm, and even resulting in abuse or assault. There are no easy solutions and these are situations in which professional help is needed, along with a dialogue with all concerned including the person with dementia if possible, including but not limited to an assessment of the likely risks and benefits of respecting the person's wishes. Above all, carers should not be left to manage this situation alone and their own dignity, wellbeing and autonomy must be considered³.

³ For further information about dealing with ethical dilemmas linked to dementia care and a commentary from an ethicist to a vignette concerning continence care, please see: <http://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice>



4

4 Statements from people with dementia and carers

In the previous sections, we have provided background information about this report, about dementia and continence problems and explored some of the challenges faced by people with dementia and carers in relation to continence care at home. In this section, we provide statements which reflect the needs and wishes of people with dementia and their carers. These statements were initially drafted by the project working group, which included a person with dementia and an informal carer, on the basis of available literature and personal experience. The eleven members of the European Working Group of People with Dementia and their carers were subsequently consulted and they approved the following statements.

4.1 People with dementia

We would appreciate a sensitive but pragmatic approach to continence issues and dementia, so that both these issues are recognised as medical conditions with physical, social, economic and emotional consequences.

People with dementia have a lot to offer. We would like to live as normal a life as possible and to remain active and equally valued members of society.

We would like to live independently and avoid being unnecessarily dependent on others.

For this to be possible, we need appropriate care, support and treatment for dementia and also for continence problems, if and when necessary, from healthcare professionals who have knowledge of both conditions.

We would like appropriate support for our relatives and close friends who live with us and help us cope with continence problems.

Access to continence products if and when needed should be considered as a basic human right to ensure our dignity, well-being and good health.

We would like to have freedom of choice regarding the type and

quality of continence products offered to us. This should correspond to our needs and those of our carers. There is not one solution that fits all⁴.

People with dementia should not be dependent solely on charitable organisations for the continence products and support they need. We have a right as citizens to necessary care, support and treatment as part of our equal right to healthcare.

We do not want to be confined to the home. Incontinence care must respond to the needs and wishes of people with dementia to travel and to play an active role in the local community and wider society.

4.2 Carers

In our capacity as carers, we would like to benefit from appropriate support and training to enable us to provide continence care to the best of our abilities.

We would appreciate recognition that we do not necessarily have nursing skills, that we have our own personal limits (linked to the nature of our relationship to the person with dementia and to social, cultural, physical and emotional boundaries) and that we need varying levels and types of support to ensure continence care.

Providing continence care to a relative or close friend can have an emotional and psychological impact on carers. It is often taken for granted that we will just cope. We would appreciate greater sensitivity, understanding and support from healthcare providers with regard to such issues.

Difficulties with communication and understanding sometimes result in people with dementia resisting assistance from carers. In such cases, assistance from professionals should be provided.

Carers often incur or share certain costs linked to the provision of continence care, such as laundry and cleaning costs, adaptations to the home, transportation costs linked to accompanying the person with dementia to consultations and lost time in paid employment. We would appreciate recognition of the financial impact of continence care on carers and appropriate compensatory measures where appropriate.

⁴ The need for freedom of choice is highlighted in the International Standard (ISO 15621) on "urine-absorbing aids – general guidelines on evaluation".



5

5 Guidelines

The following guidelines are targeted at a wide audience (e.g. health and social care professionals, carers, people with dementia and policy makers) and divided into three key themes: 1. detection, 2. continence assessment, 3. management of continence problems.

Unless otherwise stated, the guidelines are targeted at any person actually or potentially involved in the detection, assessment or care of people with dementia and continence problems living at home. Sections which are more specifically targeted at people with dementia and/or carers have **blue** colour-coded subheadings and those for GPs or health and social care professionals have **green** colour-coded subheadings. Other target groups (i.e. service providers, producers and providers of continence products and policy makers) will be highlighted in **yellow**.

Over-riding themes:

- People with dementia should have the same rights as people without dementia to the detection, assessment and management of continence problems.
- Continence care and treatment should be provided in accordance with the needs of carers and people with dementia. The aim is to try to do what is best for the person with dementia and avoid doing harm. This must take into consideration their individuality, promote autonomy, wellbeing and independent living through the provision of appropriate and individualised assessment and care.
- People with dementia should be involved in decisions relating to all aspects of their assessment, care and treatment, irrespective of their level of capacity⁵.
- Care should be considered as an on-going dynamic process often requiring re-assessment.
- A best interests, person-centred approach should be ensured if the person with dementia lacks the capacity to make a particular decision about their care.
- The correct procedure (i.e. in relation to proxy decision making) should be followed in situations where it has been established by relevant experts that the person with dementia lacks the capacity to make a particular decision about their care. This will differ in each country depending on national legislation covering decision making in the case of incapacity.
- Measures should be taken to increase the awareness, training and education of professional and informal carers about continence problems experienced by people with dementia living at home.
- The valuable role that many carers play in dealing with continence problems amongst people with dementia living at home should be acknowledged.

In relation to the above, the following European and international documents provide useful guidance⁶:

- The European charter (116) of the rights and responsibilities of older people in need of long-term care and assistance (2010)

- The European quality framework (117) for long-term care services: principles and guidelines for the wellbeing and dignity of older people in need of care and assistance (2013)
- The United Nations (21) Convention on the Rights of Persons with Disabilities (2006)
- The Council of Europe (118) Convention on Human Rights and Bio-medicine (1997)

5.1 Detection

> Look for signs of continence problems

It is important to look for signs of continence problems as some people with dementia and their carers hide such problems or are reluctant to consult a doctor. There are several possible reasons for this, including:

- embarrassment, shame or perceived stigma,
- lack of knowledge regarding care options,
- a perception that incontinence is normal with dementia or ageing.

Some people with dementia may be unaware that they have continence problems or have difficulty communicating the problems they are experiencing in relation to it. Although there could be other reasons, the following signs might indicate difficulties maintaining continence or dealing with incontinence:

The person with dementia may:

- spend a long time in the toilet,
- have lower urinary tract symptoms (e.g. frequent urination, rushing to the toilet to urinate, hesitancy, itching, “after dribble” and pain),
- be getting up to pass urine more frequently at night (nocturia) (perhaps accompanied by daytime sleeping),
- change his/her clothes frequently or at unusual times,
- use sanitary towels (in the absence of menstruation),
- not want to go out, particularly to unfamiliar places,
- be reluctant to drink or eat,
- sometimes vomit or have pain (this can happen with severe constipation),
- use natural remedies (e.g. against diarrhoea or constipation),
- have soiled laundry/stained underwear,
- be restless, agitated or anxious,
- have poor hygiene routines.

You notice:

- wet patches or stains on furniture,
- soiled laundry and toilet paper in strange places (perhaps hidden or forgotten),
- unpleasant smells,
- a mess in the bathroom/toilet,
- a change in frequency of elimination (a person should normally pass faeces between 3 times per day and 3 times per week, and

⁵ For further information, see: Alzheimer Scotland (2012). Dementia: making decisions - A practical guide for family members and friends with powers of attorney, guardianship or deputyship. Alzheimer Scotland (<http://www.alzscot.org/assets/0000/5331/Dementia-Making-Decisions.pdf>).

⁶ These documents can all be downloaded freely from the Internet. Please see the references section of this report.

urinate about 6 or 7 times a day⁷ but there are considerable differences in how often people go to the toilet).

> Ask

Carers:

If you notice any of the above signs, ask the person with dementia about them and about any difficulties they might be experiencing in relation to continence (provided this would be appropriate based on your personal relationship to the person with dementia).

GPs:

GPs should adopt a proactive approach to the identification of continence problems amongst people with dementia and keep a record of cases. They should ask about continence when a person is diagnosed with dementia and from time to time thereafter. If an older person is diagnosed with incontinence, GPs should ask about possible symptoms which might suggest the need for an assessment for dementia.

In general:

Approach the topic of continence problems with great sensitivity and with consideration for the feelings and psychological wellbeing of the person with dementia (and in the case of health and social care professionals, also of their carers).

If the person with dementia is unable to understand or respond, consider whether it would be appropriate to ask their carer or another relevant person.

Do not avoid the topic of continence problems solely on the grounds that it is a sensitive topic or that it is perceived as a social stigma.

> *Contribute towards raising awareness and challenging stigma*

Stigma may be experienced by the person with dementia and continence problems but also by relatives and close friends due to their association with them. Many people with dementia who live at home have limited contact with health and social care professionals who might otherwise notice signs of continence problems

Raise awareness about continence problems experienced by people with dementia living at home, emphasising, for example, that:

- continence problems may be linked to dementia,
- in the early and mild stages of dementia, continence problems are often related to problems with mobility, finding the toilet and toileting skills and these factors can sometimes be improved or resolved. In severe dementia, incontinence is the inevitable consequence of complete care dependence and loss of cognitive function,
- continence problems can have a social, psychological, emotional and economic impact on the lives of those who experience it and

on their families, friends and carers,

- continence problems can in many cases be successfully treated or managed (please see section 5.3),
- with appropriate care, people with dementia who have continence problems should be able to continue to enjoy a good quality of life within the community.

Challenge the stigma of both conditions and empower people with dementia and their carers to do likewise.

Box 1:

Challenging the stigma of dementia and continence problems

Avoid reducing people to either condition by the way you refer to them or by focusing solely on continence problems or dementia.

Avoid stereotypes of dementia and/or continence problems (e.g. the stereotypes of advanced dementia, of all people with dementia being incontinent and of people with dementia having no quality of life).

Bear in mind that anyone can develop dementia or continence problems and that people with these conditions and those without are all part of the same society.

Realise that men and women of all ages can experience continence problems and that this can in many cases be effectively managed or treated. It is not something to be ashamed of and does not make a person any less valuable.

Ensure that people with dementia and continence problems benefit from the same level of respect, care, treatment and participation in society as that granted to other people.

Challenge any form of discrimination against people with dementia and continence problems (e.g. factors which limit their full participation in society, result in social exclusion or result in devaluation or loss of social status).

The continence care of people with dementia living at home necessitates an interdisciplinary approach. Awareness raising should also be targeted at health and social care professionals as many lack the necessary knowledge and expertise.

> Be proactive

Carers and people with dementia:

Be aware that incontinence can be part of dementia, especially in advanced dementia, but do not consider it is as inevitable as much can be done to help people with dementia retain continence and independence as long as possible.

⁷ See: <http://www.bladderandbowelfoundation.org>

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Speak out and seek help when needed.

Insist on an assessment when experiencing continence problems. Talk to your GP about this.

Try to break the vicious circle of stigma by addressing continence problems in a pragmatic and direct manner. This may help others to do likewise.

Consider the possible benefits of writing an advance directive or statement of values whilst you (the person with dementia) have the capacity to do so in which you indicate your preferences and wishes regarding your future care. This should be done in the context of on-going advanced care planning (rather than a one-off conversation) and with the help of a healthcare professional. These documents do not have to be limited to end-of-life decision making and can be helpful to people who would like to respect your wishes.

Health and social care professionals:

Discuss the issue of advance care planning with people with dementia whilst they still have sufficient capacity to participate actively in such planning.

Ensure that you seek appropriate consent to engage in anticipatory care planning.

Ensure that you have the appropriate education and training in anticipatory care planning for people with dementia.

5.2 Continence assessment

5.2.1 Initial continence assessment

A continence assessment is initially undertaken for the following reasons:

- to identify potentially reversible causes and contributing or aggravating factors,
- to determine the need for further investigation or specialist referral,
- to develop a personalised management or treatment plan for the person involved.

There are a number of people who could conduct an initial continence assessment. Depending on the country in which the assessment is made, this might, for example, be a GP, a continence nurse advisor or a nurse practitioner specialized in incontinence. The most important thing is that the assessment is made by a healthcare professional who is specially educated in incontinence and has the ability and responsibility to direct people to the right specialists if needed. For more information about the optimal care pathway for people with incontinence, please see the Optimum Continence Service Specification⁸.

A person with dementia could also be referred to the following professionals:

- a urologist – specialist in the field of bladder problems, prostate problems and male sexual organs,
- a urogynaecologist – a specialist in the field of women's bladder and reproductive organ problems,
- a neurologist – a specialist who deals with the nervous system throughout the body,
- an elderly care physician – a specialist in the field of medicine for elderly people.

> Involve people with dementia and carers in the assessment as far as possible

People with dementia and carers:

People with dementia (or their carer if necessary) who go to see their GP about continence problems should tell or remind the GP that they have dementia. If referred to a specialist, they should also inform the specialist that they have dementia in case the GP has not already done so.

Health and social care professionals:

People with dementia who are experiencing difficulties with continence should be offered a continence assessment and, for those in the older age group, a comprehensive geriatric assessment⁹.

People with a subjective memory complaint or mild cognitive impairment, who have not been diagnosed with dementia but are experiencing continence problems, should be offered a cognitive assessment.

The person responsible for conducting the first assessment should be informed of the person's diagnosis of dementia.

Health and social care professionals should involve people with dementia and carers in the initial continence assessment as far as possible. In order to achieve this, they should ensure that their procedure and personal approach is adapted to the needs of people with dementia and their carers. If necessary, they should seek training in how to communicate with people with dementia.

Health and social care professionals involved in the initial assessment should:

- start from the assumption that people with dementia should be involved in the assessment process for continence problems,
- encourage the involvement of a carer or trusted person in the assessment process as a means of support (e.g. to provide information that the person with dementia might not be aware of, to support him/her in understanding, making decisions and communicating, to keep a record of what was decided and to be aware of the next steps),
- be sensitive to the right of people with dementia to choose who should be consulted about their care. Respect their right to privacy

⁸ For a free summary of the Optimum Continence Service Specification, please see: <http://www.gfiforum.com/Documents/Madrid-2014/Summary%20of%20Optimum%20Continence%20Service%20Specification.pdf>

⁹ For more details about comprehensive geriatric assessments, please see: http://www.medscape.com/viewarticle/465308_4

and confidentiality. In some cases, this may be partly influenced by decisions made in the context of a power or attorney or guardianship measure,

- not presume that a person with dementia is incapable of providing information and of explaining possible problems with continence,
- not assume that the person with dementia lacks capacity simply because his/her decision seems unwise or unusual,
- take measures to maximise the potential of people with dementia to communicate their needs, wishes and difficulties in relation to continence (see Box 2),
- ask the carer if the person with dementia cannot understand or answer questions, or there are doubts as to the accuracy of the information provided,
- give the carer the opportunity to comment if s/he is indicating that the responses from the person with dementia are incorrect,
- find out if the person with dementia has an advance directive if they lack the capacity to consent to a particular examination which might eventually be proposed and about carers' needs, willingness to provide care and coping skills,
- assess the level of dependency of the person with dementia on other people or home care services to achieve continence or deal with incontinence,
- consider issues related to the accessibility/affordability of the assessment and any referrals.

Box 2:

Measures to facilitate communication and support decision-making

Speak slowly and clearly but without exaggerating.
Maintain eye contact.

Find a quiet place with no distractions for the discussion.

Adapt your language to the perceived level of understanding of the person with dementia.

Give the person enough time to respond.
Ask one question at a time.

Avoid overloading the person with too much information at once.
Help the person to express what is currently important to them.

Feed information back to check that you have understood and to remind the person with dementia what has been said so far.

Use any relevant materials (e.g. objects, brochures and notes).

Look out for signs of fatigue, confusion or lack of concentration.

Provide reassurance, if needed, through appropriate touch, body language and tone of voice.

> Aim for equity in the assessment process

A proper continence assessment, diagnosis and initial treatment for continence problems should be offered irrespective of whether a person has dementia, is advanced in age, lives alone or any other discriminatory criteria.

Start from the assumption that people with dementia should be eligible for any tests that would routinely be carried out, as well as for referrals. They should have the same right to consult a specialist for continence problems and have relevant examinations as any other person.

> Carry out a thorough continence assessment and ensure that there is follow up

Health and social care professionals:

Ideally, assessments should be carried out by healthcare professionals with knowledge of both dementia and continence problems. The availability of healthcare professionals and services with specific expertise in continence assessment and management will vary from country to country.

Healthcare professionals should follow recognised guidelines on the clinical assessment of continence problems, which are officially recognised by the healthcare authorities in their countries. In the absence of such guidelines, European or internationally recognised guidelines may be helpful such as the ICI clinical guidelines, which are revised every four years and are for this reason up to date with the latest clinical findings. When carrying out an assessment, the following issues should be considered:

- the type of incontinence,
- the severity (i.e. is it a small or large amount of urine or faeces?),
- current medication (an analysis of dosage, possible interactions),
- the involvement of continence nurses/advisors (if available) who may be well placed to take on the role of case coordinator during the care pathway,
- the need for referral to secondary care or a hospital specialist,
- the need for continence products to support independence which meet the needs of the person with dementia and his/her possible carers,
- the person's medical, surgical, obstetric, urologic, gynaecologic, and neurologic history.

> Prepare yourself for a continence assessment or to accompany a person with dementia for an assessment or consultation in relation to continence issues

People with dementia and carers:

In order to determine the cause of factors contributing to continence problems, people with dementia should be offered a continence assessment/consultation to discuss these issues and for the doctor to examine them. The following information is intended to

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help people with dementia and their carers prepare for an assessment and know what to expect.

1. During this assessment/consultation, the person with dementia or carer may be asked about various symptoms (combinations of which might indicate more than one diagnosis) and for basic information about toileting habits.

- Symptoms that may indicate stress urinary incontinence (SUI):
 - leakage on coughing/laughing/sneezing
- Symptoms that may indicate an overactive bladder (OAB):
 - frequency (voiding >8x per day)
 - urgency – rushing to get to the toilet
 - urge incontinence (not making it to the toilet on time)
- Symptoms of nocturia (getting up >1x at night to pass urine)
- Symptoms that may indicate bladder outflow obstruction:
 - hesitancy (waiting some time before the urine flows)
 - poor stream (slow flow of urine)
 - incomplete bladder emptying (feeling the need to go again after having just been)
- Symptoms that may indicate a recurrent urinary tract infection (UTI):
 - pain during urination
 - urine has a penetrating smell
 - an imperative/urge feeling
- Symptoms that indicate problems with bowel elimination:
 - hard stools or long periods of time between opening bowels
 - pain
 - faecal leakage (liquid or normal stool)
- The duration of the incontinence episodes (i.e. whether the incontinence is considered transient or established),
- The degree of incontinence (in terms of quantity and frequency),
- The person's toileting routine and diet (including foods which s/he includes or avoids due to continence issues).

2. The person with dementia or the carer may be asked about:

- mobility – if getting about is difficult this may impact on reaching a toilet,
- the ability of the person to manage tasks associated with toileting and maintaining continence, and the type and degree of any assistance needed to remain continent,
- whether the level of support available is sufficient,
- the impact of caring on quality of life and possible physical strain for carers,
- clothing (some people with dementia find zips and buttons difficult),
- cognition (the degree of cognitive impairment and whether there is any improvement with repetition or better understanding and awareness),
- environmental factors (i.e. toilet visibility, distance, lighting, privacy and cleanliness),
- the person's emotional responses to continence problems and/or to being assisted to maintain continence or manage incontinence,

- multiple medications (polypharmacy) – a medication review is essential including over-the-counter medications. Many drugs cause continence problems.
- co-morbidity – many other medical conditions can impact on continence such as heart problems, diabetes, chronic cough, Parkinson's disease and stroke,
- fluid intake – you may be asked to fill in a bladder diary (see section 5.3.2),
- food intake – you may be asked about what you eat and about how this might be contributing towards incontinence,
- current use and type of continence products (e.g. pads/pant, protective underwear, commodes, etc.).

There are a few questions regarding symptoms which are associated with a need for a specialist urology or gynaecology referral. In particular, this includes cases where incontinence is associated with pain, there is blood in the urine or a mass in the abdomen or if the person has had previous pelvic surgery or radiotherapy treatment, or women who have a visible prolapse. If the person with dementia has any of these symptoms, it is essential that they see a specialist.

The following samples might be required:

- blood,
- urine,
- stool.

As well as assessments of general functional and cognitive abilities, more specific physical examinations may be carried out:

- examination of external genitalia – to check for skin infection, moisture lesions where skin is sore after being wet and/or obvious prolapse,
- abdominal examination,
- vaginal examination – for internal prolapse and to assess pelvic floor muscle strength,
- rectal examination – for faecal impaction, mass in the rectum or in men a large or irregular prostate,
- a neurological examination if there are obvious neurological signs such as limb weakness (e.g. leg weakness). Nowadays a portable bladder scan can be used to measure residual volume and can be used as a part of an initial assessment to exclude retention of urine or overflow incontinence.

Health and social care professionals:

Healthcare clinicians who are conducting the assessment should take care to weigh up the relative benefit of performing the examination and the person's capacity to provide informed consent (or for a person who is authorised to do so, to provide proxy consent). The reason for caution is that unless the person with dementia can understand the rationale for a particular examination (especially a vaginal or rectal examination), they may interpret it as a form of abuse and find the experience distressing.

5.2.2 Specialist assessment

People with dementia and carers:

Depending on the doctor's analysis of the information obtained from the above-mentioned assessments and examination, the person with dementia may be asked to have additional tests such as:

- an ultrasound examination of the bladder or pelvis,
- an X-ray of the abdomen to indicate a slow transit or faecal loading (especially if the person with dementia does not understand the rationale for the rectal examination),
- a cystoscopy or cystography to allow the doctor to look at the interior lining of the bladder and the urethra,
 - urodynamic testing to measure, for example, the amount of urine and flow rate, the capacity of the bladder, bladder contractions, sphincter control and ability to empty the bladder completely. An example of such a test is the cystometrogram which measures how much the bladder can hold, the buildup of pressure and how full it is when the person feels the urge to urinate.

The above tests are not generally painful. Nevertheless, they may cause anxiety and stress to some people with dementia and this should be taken into consideration. Also, whereas some people may find them slightly embarrassing, others may find examination distressing if they do not understand fully why it is being done.

On a more practical level, the person with dementia may be required to follow instructions (e.g. to arrive for testing with a full bladder and to resist urinating until told to do so) and provide feedback during the test (e.g. regarding the urgency of their need to urinate or sensations in the bladder). This could be problematic for some people with advanced dementia. They may, for example, have difficulty understanding the initial instructions, remembering on the day to do what was requested, resisting urinating due to stress and a disruption of the notion of time, interpreting bodily sensations or communicating how they feel.

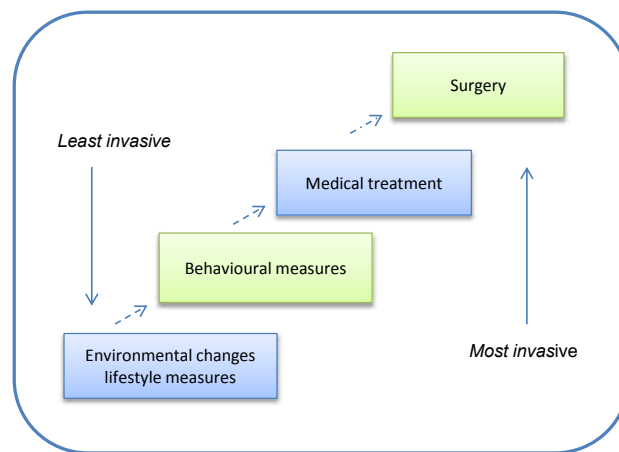
In addition, it may be necessary to find doctors and departments in different parts of a building or even in different buildings and this requires mobility, spatial orientation skills and the ability to remember and follow directions.

5.3 Management of continence problems

Once a type of incontinence or continence problem has been established, an action plan should be developed in a stepwise process (see Figure 4 below). This should involve the establishment of a coordinated care plan involving the person with dementia and all health and social care professionals (including allied professionals), as well as informal carers, providing dementia and continence care to a particular person with dementia. For this reason, although health and social care professionals play a key role in managing continence problems, the information in this section might also be

helpful for people with dementia and their carers who would like to be informed about and involved in decisions relating to various treatment and care options which might be offered.

Figure 4: Stepwise process for continence care of people with dementia at home



This is a simplistic illustration of continence management. Containment products are specifically addressed in the section “environmental changes and lifestyle measures” but should be available, if needed, along all four steps to protect the person from leakage issues. People with dementia should be considered for all appropriate interventions where safe and possible. Management usually starts with conservative measures such as lifestyle measures and environmental changes and may progress, depending on needs and wishes, through the range of options depicted above. Before looking at each in more detail, we briefly consider general issues related to: ethical care, carer support and case coordination.

Ethical care

Continence care to people with dementia at home should be provided within an ethical framework of care (see section 3.5). This includes, for example, the need to pay attention to:

- involving people with dementia in care-related decisions as far as possible,
- establishing a dialogue with everyone involved and whose participation might be helpful (whilst respecting privacy and confidentiality),
- interpreting and making sense of the issue, the situation (as an on-going process rather than a one-off decision), the capacity of the person with dementia, the values, wishes and needs of both people with dementia and their carers, and the likely risks and benefits linked to respecting the wishes of the person with dementia,
- considering ethical principles and values at stake as well as possible outcomes in relation to the lived experience of all involved,
- paying particular attention to dignity, vulnerability and people

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with dementia existing as unique individuals but in most cases within a web of relationships (1).

Carer support

In many cases, people with dementia live with relatives and friends who are heavily involved in both dementia and continence care. Support for carers of people with dementia living at home must therefore be part of any strategy to manage continence problems. This should include practical, emotional and financial support, and respite depending on each carer's needs. Carers should be given training and have a named person to whom they can turn in case of difficulty. Many carers of people with dementia are older and have their own health issues (e.g. problems with eyesight, mobility, arthritis and even life-threatening diseases which affect their ability to look after another person). Helping an adult to get to the toilet, get on and off the toilet and undo or fasten clothing, cleaning around the toilet area, washing the person with dementia and changing continence pads and bedding require physical and emotional strength, coordination, planning, dexterity and endurance. Any support provided must correspond to the real and current situation and needs of individual carers.

Case coordination

Due to the complex and changing needs associated with both dementia and incontinence, it is essential to have one person with overall responsibility for the organisation and coordination of the continence care of each person with dementia living at home. In some countries, this is a recognised post (e.g. a case coordinator or case manager). In others, it is not but a health or social care professional fulfils that role. The person who acts as case coordinator, irrespective of his/her job title and other professional duties, should have the relevant expertise in both dementia and continence care and involve people with dementia and their carers in the development of a comprehensive care plan.

In the remainder of section 5.3, we provide more detailed guidelines on the management of continence problems in the different steps described above.

5.3.1 Environmental changes and lifestyle measures

Making adaptations within the home, using various devices and products to support mobility and help deal with continence problems, as well as paying attention to food, drink and personal hygiene often have a positive impact on the management of continence problems. These approaches are addressed below.

> Consider measures linked to the environment

People with dementia and carers:

Ensure that there are no obstacles which might make it difficult to reach the toilet in time (e.g. furniture blocking the way, chairs which

are difficult to get up from, poor lighting, door which are hard to open and confusing designs on floors).

If the bathroom is too far away, consider reorganising the living areas within the home so that the distance is reduced.

Check that mirrors in the bathroom are not contributing towards the person with dementia thinking that someone else is there.

Ensure that the room in which the toilet is situated is easily recognisable. Consider a sign on the door (e.g. a realistic image, a symbol and/or words). As some people consider this inappropriate in the home, it is important to find one that fits in with the décor and is acceptable.

Consider putting a sign on the inside of the toilet door to remind the person where and why they are there.

Reassess from time to time whether the signs are still helpful.

Consider changing the colour of the toilet seat to one which provides a clear contrast to the pan of the toilet. Using a product to colour the water in the toilet blue might also be helpful.

Look into the possibility of obtaining the right to certain services for people with incontinence. Examples include a special key for the public toilets for disabled people which are kept locked, a public toilet finding device and an incontinence card which gives people access to toilets which are not open to the general public.

> Consider using assistive technology and products to promote independent toileting, safety and mobility

People with dementia and carers:

Consider using assistive technology (AT) and products designed to promote independence, safety and mobility. AT includes devices and systems which enable someone to perform a task more independently or with greater ease and safety. Box 3 provides a few examples of AT and other useful products.

Address problems with mobility and if possible treat or remedy them (e.g. through medication, AT, exercises or reorganisation of the home).

Keep any walking aids within easy reach.

Be aware that some people with dementia might not recognise or understand how to use some devices or products, however obvious it may seem and even if they used them in the past. This may sometimes lead to misunderstandings (e.g. the belief that the person with dementia is being awkward or uncooperative).

Box 3:

Examples of assistive technology and products to promote independent toileting, safety and mobility

Devices to detect moisture or movement (e.g. to detect night-time accidents or getting out of bed).

Lighting devices which react to movement and light up certain areas automatically (bearing in mind that for some people, this might be confusing or disturbing).

Devices to signal for assistance.

Locks on toilet doors which can be opened from the outside in case of emergency.

Hoists and equipment or furniture to aid lifting.

Mobility aids (walking sticks and frames, grips and rails).

Raised toilet seats and seats for the bath or shower.

> Consider using continence products (to prevent or contain incontinence)

The first aim, when considering the use of continence products to prevent or contain incontinence, should be to keep the person with dementia independent from the care of others for as long as possible and to secure independence with maximum dignity as long as possible.

The needs of the carers (and their ability to provide support) should also be considered.

People with dementia and carers:

People with dementia (and/or their carers) should seek and be provided with information about the range of continence products available for preventing or containing incontinence¹⁰. These can be broadly divided in the following categories:

- handheld urinals (different versions for men and women; urine bottles exist with a non-return valve or granules in the bottle to make urine thick and less easy to spill),
- commodes and bedpans (there may be concerns about lack of privacy, embarrassment, odour, the look of the object and the need for other people to empty it),
- absorbent products (such as insert pads/pants, protective underwear and male pouches),
- body-worn urinals (e.g. sheaths for men, exist for women but not widely available),
- urine drainage bags (worn on the leg or body, or hooked to a stand),
- catheters (indwelling catheters should not be the first or long-term choice. Catheters should not be used only for the conven-

ience of the carers but when a person cannot empty the bladder and when medically required),

- occlusive devices (to block/prevent leakage such as a special tampon for women or for men, a device to compress the penis),
- plugs to prevent leakage of faeces,
- devices to channel faeces into a container,
- pads to contain faeces.

People with dementia may need time to come to terms with the psychosocial implications of using products to prevent or contain incontinence and should not feel guilty or be blamed if reluctant to use them.

Some products are more discreet than others and it is understandable that this is likely to influence choice. However, when selecting an absorbent product (e.g. a pad/pant or protective underwear), the extent to which it provides the level of protection (i.e. absorbency, odour) required, as well as the skin-friendliness of the product and its ease of use should be key considerations.

Health and social care professionals:

When proposing various containment products, be sensitive to what their use might symbolise to some people with dementia (e.g. in relation to dignity, control, adult status and the stage of dementia) and to possible fear linked to a perceived association between incontinence, advanced dementia and entry into a residential/nursing home.

People with dementia should be offered continence products that are appropriate for their specific needs, readily available and affordable, and which contribute towards the maintenance of independence.

Choice should not be restricted to products which have been pre-selected by healthcare providers based on criteria which are not linked to individual needs (i.e. that are solely based on tendering practices or costs) or are of the lowest quality. A “one size fits all” approach should be avoided.

Products that resemble typical underwear/pants should be available in addition to diaper-type solutions with tapes as the former tend to be more user-friendly for people with cognitive impairment and may make it easy for them to go to the toilet independently.

Health and social care professionals (ideally a continence advisor/nurse) should provide advice on the different options available, demonstrate how to use them if necessary and give advice on how to look after the skin, reduce the risk of infections linked to the use of certain products and dispose of pads. Brochures, DVDs and websites might, in addition, be helpful as they can be watched in private and when convenient.

¹⁰ See chapter on “Management with continence problems” by Cottenden et al. (104) for detailed information on this topic.

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A trained professional in continence care (such as a continence advisor/nurse) should be involved in continence assessments and the initial treatment, and should assist people with dementia in the choice of an appropriate containment product (if needed). Support should also be organised to enable the person to manage his/her continence whilst living at home.

People with dementia should have the opportunity to try different types, sizes, absorbency, quality of containment products in order to find those which are best suited to their needs (before investing in larger quantities of a particular product). This could perhaps be organised through day care centres, through the supply of samples and by continence advisors/nurses and general nurses.

People with dementia should not be encumbered with products that are not appropriate and might never be needed as this is wasteful and may be demoralising.

People with dementia may have difficulty planning orders of containment products. Greater flexibility may be needed, including the possibility for last minute orders and some external monitoring (e.g. home care service workers keeping an eye on supplies).

People with dementia should not be arbitrarily restricted to a predetermined number of containment products, especially continence pads (e.g. through the healthcare insurance or healthcare service). If a person needs more products because this corresponds to their needs, it would be unethical not to provide them and would represent a failure to respect his/her human dignity. On the other hand, some people use more pads per day than necessary and this could be considered as uneconomical, not ecological and putting a strain on carers. In case of uncertainty, consultation with a continence advisor/nurse or a person fulfilling that role, would be beneficial.

Producers and suppliers of continence products:

Producers and suppliers of products to prevent and contain incontinent should:

- ensure that the product packaging is discreet, positive and easy to open,
- make products available in small and larger quantities,
- consider the distribution of absorbent products (i.e. pads/pants and protective underwear etc.) in supermarkets, alongside other hygiene and sanitary products,
- design emergency and travel kits for people with dementia and continence problems (e.g. discreet/pleasantly designed bags for men and women which they can separate from their main luggage when needed or carry separately, containing a pad, a plastic sealable bag for the used pad, hygienic wipes and cloths to wipe hands),
- consult people with dementia and carers in the development of continence products,

- consider developing innovative products, in terms of aesthetics, colour, material, ease of use and size in order to increase compliance and to target the specific needs of people with dementia and to promote independent living and social inclusion.

> Pay attention to diet and fluid intake

People with dementia and carers:

People with dementia (and/or their carers) should try to ensure that:

- they have access to a sufficient amount of liquids and that they are drinking. Fluid intake is important in relation to both urinary and faecal incontinence. People with dementia may forget to drink, not feel thirsty or avoid drinking in an attempt to remain continent. Do not restrict drinks in general as a means to prevent incontinence as this can be dangerous but limit drinks two hours before sleeping,
- they are eating a sufficient amount of fibre (e.g. whole grains, bran, raw fruit and vegetables). The Bristol stool chart¹¹ may be helpful in monitoring possible problems with intestinal transit,
- they pay attention to their diet and particularly to fibre intake as a means to manage faecal incontinence.

> Take measures to promote hygiene

People with dementia and carers:

Establish general hygiene routines and skin protection (see Box 4). Take into consideration the capacity to maintain hygiene, the availability of support and the willingness of the person with dementia to accept outside help.

For some older people with mature skin, skin cleansers may be preferable to soap and water, when cleaning themselves after an accident, and some studies have found that this helps prevent incontinence-related skin problems (127). There are several products on the market (e.g. wash mousse and wash gloves) that are very skin friendly and can be used not only after an accident (either urinary or faecal) but as a general measure when cleaning the perineal area (the area between the anus and either the vulva or the scrotum).

¹¹ For more information, see: http://www.gutsense.org/constipation/normal_stools.html

Box 4:¹²

Maintaining good hygiene and protection of the skin

Put on clean underwear every day.

Consider cotton loose-fitting underwear which does not have elastic around the leg area. However, if using continence pads, tighter fitting underwear is necessary to hold the pad in place.

To prevent irritation or damage to the skin, try to provide gentle cleansing (avoiding soap if possible) and avoid prolonged wetness and skin contact with urine or faeces and especially combined contact with both urine and faeces.

Keep the skin moisturized and apply a skin protection or moisture barrier.

If used, change continence pads/pants and protective underwear regularly.

Ensure the correct pad is used. This should be advised by a healthcare or social care professional with a good knowledge of both continence problems and dementia. Each person should be provided with a product which is best suited to their individual needs.

Regularly check the skin for possible damage, irritations or chaffing.

Avoid douching unless instructed to do so by a healthcare professional.

When wiping around the anus after having been to the toilet, wipe from front to back in order to minimise the risk of infection in other areas (such as the urethra and vagina for women).

At least once a day and always after urinary or faecal incontinence, wash the perineal area (the area between the anus and either the vulva or the scrotum).

To avoid damage to the skin in this delicate area, use warm water, a mild, unscented soap and pat dry. Do not rub or apply powder. If possible, avoid the use of soap. Impregnated wash gloves are skin friendly and may be easier to use as there is no need to rinse and dry.

Avoid scented toilet tissue.

Report any foul smell, itching or bleeding to a doctor.

Drink plenty of water to keep the urine less concentrated and well hydrated skin tissue.

Seek professional help if the person with dementia is unable to take care of their intimate personal hygiene, refuses assistance and you are concerned about their wellbeing or that you cannot cope.

If the person with dementia already has incontinence-associated dermatitis (IAD), contact a healthcare professional who will normally establish a treatment plan, which may involve “protecting the skin from further damage, establishing a healing environment and eradicating any cutaneous infection” (125).

5.3.2 Behavioural measures

Most people, including those with dementia, wish to maintain independent bladder and bowel function and to go to the toilet at a time of their choosing, on their own and privately. However, people with dementia may at some point need assistance. The level of assistance needed will vary widely (e.g. some people may require prompting and others may require physical assistance). It is not easy for people to accept being assisted to use the toilet or to wear pads. Carers need to recognise what level of assistance is needed and when. This may alter from day to day.

> Recognise toileting needs and provide support if needed

People with dementia and carers:

Establish regular toilet routines, based on each person’s typical daily routine.

As people with dementia have different needs with regard to toileting (and may experience urgency), avoid sticking too rigidly to set toilet times (e.g. every three hours irrespective of the person’s needs and habits) (unless this is part of a training plan – see section on timed voiding below).

Try to ensure that assistance is available if and when needed. Some people have predictable times they need to go to the toilet. Others do not. However, most people, regardless of whether they have dementia, need to go to the toilet 4-6 times over 24 hours, and once at night if they are over the age of 60. Therefore, it might be helpful to prompt or assist the person with dementia (if they need this support) to go to the toilet when they wake up in the morning, after breakfast, around lunchtime, once in the afternoon, again in the evening and before bed.

Try to recognise and assess signs that the person with dementia may need to go to the toilet as perhaps s/he is unable to communicate the need or is not sufficiently aware of it and prompt the person to use the toilet using appropriate communication skills. Such signs might include a different posture, pulling at clothes, anxiety, restlessness, fidgeting or a worried expression. However, it is important to consider the possibility that some of these signs might for some people be an expression of pain or psychological distress.

¹² Adapted from Palmer (1996) (see reference 119).

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To tailor assistance to individual needs, it may be helpful for the person with dementia (with the help of a carer if necessary) to keep a bladder diary. This records liquid intake and urine output (e.g. frequency, amount, urgency, accidents and circumstances surrounding any accidents). It is important to do this for at least three days, as any one day might not be typical. Each day should cover a full 24-hour period and start from the same time each day (e.g. from 08.00 one morning to 08.00 the following morning).

Respect the person's autonomy by accepting his/her decision whatever that may be. If a person with dementia resists carers' attempts to assist them to the toilet, carers should interpret this response as the person's desire and right to maintain optimal independence.

Try to find trousers and underwear that are easy to undo or release (e.g. Velcro or elasticated waists) in order to reduce the likelihood of accidents occurring due to unnecessary delays. However, the individuality, dignity, comfort and right to self-expression of people with dementia should be respected.

Ask a doctor or continence nurse/advisor about different types of exercises and training to help prevent accidents such as timed voiding, prompted voiding, bladder retraining, habit retraining and pelvic floor exercises.

- **Timed voiding:** This is where the person is toileted regularly by their carer for example twice hourly and voiding is recorded. The time between voiding is fixed during the training. A voiding schedule can then be charted to match the individual's voiding pattern,
- **Prompted voiding:** This is where the person is asked by their carer on a regular basis if they need toileting assistance. There should be regular monitoring and people encouraged to report their continence status. It is important to provide positive reinforcement for maintaining continence and to look for non-verbal cues for toileting need,
- **Bladder retraining:** This involves, with the help of a carer, slowly increasing the time between voids, learning to control the urge and consequently the number of trips to the toilet. Again, it is important to provide positive reinforcement,
- **Habit retraining:** This involves identifying the person's natural voiding pattern and with the help of a carer developing an individualized toileting schedule to prevent accidents from occurring,
- **Pelvic Floor Muscle Training (PFMT):** In people who are motivated and physically more able, PFMT exercises should be considered and can benefit stress urinary incontinence and urge urinary incontinence. The aim is, with the help of a trained health care professional, either to teach the person how to make pelvic floor muscle stronger and increase strength, endurance and coordination of muscle activity, or when the muscles are contracted to help relaxation of those muscles.

Health and social care professionals:

Toileting strategies have been tried with varying success in dementia.

Factors such as the severity of cognitive impairment, problems with mobility and the frequency of incontinence reduce their benefit (120). However, they may be beneficial to some people provided they are adapted to individual needs (e.g. based on the person's capacity, the availability of assistance, a person's voiding diary and other related factors such as bladder volume and fluid intake). Consequently, pelvic floor exercises and the various forms of training mentioned above should be offered, where appropriate, and funded by healthcare insurance companies and national health and social care systems. Nevertheless, it is also worth considering that these regimes can lead to irritation as the person with dementia may perceive this as being treated like a child (52) but in some cases, carers find it burdensome and this may contribute towards their decision to relinquish care (5).

Often, combinations of lifestyle measures and behavioural therapies will significantly improve continence issues.

> *Support carers*

Providers of continence care:

Provide carers helping a person with dementia and continence problems with:

- practical support in continence care (e.g. help from a professional carer),
- training/courses in continence care,
- psychological and emotional counselling,
- access to assistive technology, products to promote independent toileting, safety and mobility, and products to prevent and contain incontinence,
- assistance with laundry,
- subsidies for equipment and costs incurred,
- respite (e.g. day care for the person with dementia or temporary replacement of the carer away or in the home),
- flexible support and services (also to the person with dementia directly).

The importance of taboos, unspoken rules within families about levels of physical contact, gender issues, cultural factors and health conditions amongst carers providing continence care to person with dementia should not be underestimated. These factors may contribute towards decisions for the person with dementia to move into a residential or nursing home.

Counselling should cover a range of psychological and emotional issues such as dealing with despair, feeling degraded, fears about not being able to cope and managing feelings of disgust. The importance of such factors should not be underestimated.

The ability and willingness of carers to undertake various tasks linked to continence care should be considered when proposing various measures. It should not be presumed that carers will accept responsibility for such tasks.

Health and social care professionals:

Healthcare professionals who were responsible for the initial and any subsequent assessments should follow up the person with dementia and/or carers with regard to the effectiveness and satisfaction with any care or referrals provided.

5.3.3 Medical treatment and surgery

People with dementia and carers:

People with dementia and carers should be aware that in addition to environmental changes, and both lifestyle and behavioural measures, people with incontinence may benefit from a range of medical treatment options and surgery.

A second opinion should be sought in case of doubt about unjustifiable refusal to consider medical treatment and surgical options based solely on the person having dementia.

Proxy decision makers:

People who are authorised to make a decision on behalf of a person with dementia lacking capacity should balance likely risk and the person's right to take certain risks with likely benefit based on knowledge of that person and his/her previously and currently expressed wishes, subject to national legislation governing substitute decision making.

Health and social care professionals:

An overriding principle should be to assess potential risk against potential benefit and quality of life of the person with dementia. People with dementia should be given the opportunity to benefit from medical treatment or surgery on an individual basis.

People with dementia should not be denied the possibility to access certain interventions solely on the grounds that there is a risk. They have the right to make an informed decision to accept certain risks if they have the necessary capacity to make that decision.

Healthcare professionals (e.g. GPs, specialists and continence advisors/nurses as well as relevant allied health professionals¹³) should consider the following issues in relation to treatment and surgery for people with dementia and continence problems living at home:

- As with assessment, when reflecting on possible treatment or surgery for continence problems, start from the assumption that people with dementia have the same needs and rights as other patients,
- Consider whether possible treatment and surgery options are compatible with individual patients with dementia,
- Do not rely solely on generalised data about the remaining life expectancy (RLE) of people with dementia which is reportedly lower than for people without dementia or affected by frailty and cognitive impairment¹⁴. An individual and comprehensive assessment is needed, bearing in mind that dementia is increasingly being

diagnosed at an earlier stage,

- Consider how to maximise the potential of people with dementia to stay at home,
- Consider ways to address potential barriers to different options (e.g. based on capacity, communication, mobility, available support and consent) for individuals with dementia living at home,
- Avoid stereotypes and assumptions (e.g. that a person with dementia will be unable to follow instructions),
- Inform people with dementia and their carers or legal representatives about possible or likely risks associated with specific medical treatment or surgery,
- The most invasive/potentially risky management options, such as surgery, may be considered by specialists. Surgery for incontinence involving people with dementia should only be carried out in hospitals by health care teams that also have knowledge and experience of dementia,
- Try to find out from people with dementia and carers, following treatment and surgery, whether they feel that it was of benefit to them,
- Adhere to clinical guidelines covering the full range of treatment options for different types of incontinence, including pelvic floor exercises, as well as on the use of containment products (e.g. ISO 15621) in the context of patients' and carers' needs, as approached from a holistic perspective,
- Adhere to guidelines about using catheters (e.g. the 2013 EAU guidelines). Indwelling urinary catheters should not be used unless there is a clinical indication (such as in the case of a wound or if the bladder cannot contract any more), only as a last resort and should be removed as soon as clinically warranted. It should be considered that the person with dementia might not understand or accept the medical rationale for the catheter. If the catheter is uncomfortable, they may attempt to remove it and damage the urethra (or prostate). Sometimes, when a catheter is absolutely necessary, a tight body stocking may help prevent such attempts.

Specifically in relation to the use of medical drugs (see section 2.4 for background information):

- Carry out a regular review of medication, of compliance with it and of possible drug combinations which might have an adverse effect on continence,
- Before prescribing drugs for older people, consult established clinical guidelines such as the Beers Criteria (see reference 121 for details of latest update),
- Only prescribe medication for UI to people with dementia if more conservative management has failed and if so, ensure that they are carefully monitored by a specialist. The use of anticholinergics in combination with dementia drugs (cholinesterase inhibitors) is still controversial,
- Establish continence status before prescribing cholinesterase inhibitors for dementia as if someone develops UI, reducing the dose or stopping the drugs may be beneficial,
- Devise measures to ensure drug compliance,

¹³ a whole range of health professionals, who do not fall into the categories of nursing, medicine or pharmacy, but who are part of health care teams.

¹⁴ Larson et al. (2004) cited in Wagg et al. (2013).

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- Consider changing the drug regime, especially of older people with dementia and incontinence, before adding another drug to target incontinence,
- Be aware that some psychotropic drugs may cause confusion and impaired mobility and also precipitate urinary incontinence.



6

6 What do we need from service providers and policy makers?

Guidelines for people with dementia and continence problems living at home are unlikely to be effective in the absence of a coordinated framework and health and social care professionals with an understanding of both conditions. All too often, the carers of people with dementia and continence problems living at home are expected to provide continence care even though they have received no training, may have difficulty coping with such intimate care and may have additional family and professional responsibilities. Service providers, such as the healthcare system, municipalities and healthcare insurance companies (depending on national healthcare funding systems), should therefore ensure that people with dementia and their carers where appropriate:

- have access to information about dementia (e.g. causes, symptoms, possible future difficulties with continence) and support and training in the period following diagnosis to help ensure that the person with dementia can be cared for in the community for as long as possible,
- have access to the full range of continence care options (e.g. containment products, care, training, medication and surgery) to enable them to live at home independently for as long as possible and with dignity,
- are put in contact with health and social care professionals with joint expertise in dementia and continence care,
- are aware of the options available to them to help deal with continence problems,
- are not left with sole responsibility for care that they are not willing or able to provide (especially intimate care provided by carers),
- are not lacking necessary products to prevent and contain incontinence due to their lack of economic means.

In relation to health and social care professionals and the framework of continence care, service providers should:

- ensure the provision of integrated social and health care for conti-

nence problems which is adapted to the specific needs and wishes of people with dementia living at home,

- involve incontinence nurses/advisors and nurses who are specialised in continence care in the care of people with dementia and continence problems living at home,
- ensure that the framework and payment system for consultations, assessment and the provision of support, care and treatment for incontinence allow sufficient time to address the additional needs of people with dementia,
- provide appropriate training to ensure that there is a sufficient number of health and social care professionals with joint expertise in dementia and continence care,
- increase funding to carry out studies about incontinence in people with dementia with a specific focus on prevalence, incidence, the impact on people with dementia and their carers, community perceptions, evaluation of existing continence and community services and effectiveness of innovative treatment modalities.

In relation to the wider social context, service providers should:

- raise awareness about dementia and continence problems amongst people living at home, and address the stigma of both conditions,
- take the necessary measures to enable people with dementia and continence problems to move about freely within the community,
- enhance dementia-friendly environments, taking into account the specific problems faced by community-dwelling people with dementia with continence problems,
- consider the need for unisex public toilets for disabled people to enable carers to provide assistance if needed,
- provide hygienic wipes in vending machines and install containers for disposable pads in disabled toilets as well as in toilets for women and for men,
- ensure that architects are sufficiently trained to understand the needs of people with dementia (e.g. related to cognitive impairments, possible continence problems and mobility issues within the home).



7

7 Conclusion

People with dementia must have the same opportunity as other citizens to receive assessment, care and treatment, should they at some point experience continence problems. Assessment and various forms of care and treatment offered must be based on a thorough understanding of both dementia and continence problems. Assessment, care and treatment options should not be restricted solely on the grounds that a person has dementia. They must be based on what would be in the best interests of each person with dementia (i.e. taking into account their individual needs, wishes,

condition and situation). Health and social care professionals and service providers must also take into consideration the needs and wishes of informal carers who often play a vital role in ensuring good continence care for people with dementia living at home.

In this report and the guidelines, we have highlighted some of the main issues of relevance to combined dementia and continence care at home, as well as some of the challenges of living with these conditions or providing such care. We hope that this report will contribute towards improving the continence care of people with dementia living at home.



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The continence care of people with dementia living at home should be understood within the global context of the long-term care of people with complex care needs. This requires a collaborative approach involving social and healthcare professionals in co-operation with people with dementia and their informal carers. Moreover, it is important that social and healthcare professionals have the necessary expertise and experience of both continence care and dementia.

This report contains background information about dementia and continence care, explores the experience and challenges faced by people with dementia and their carers and contains statements about the kind of support they would like to receive. The last section of the report contains guidelines targeted at people with dementia and their carers, social and healthcare professionals, and policy makers and service providers. The guidelines are organised into three main sections covering detection, continence assessment and the management of continence problems.