In this article...

- Why we need to change how we think about incontinence
- The five key outcomes of good continence care
- How the resource affects people with continence problems

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An assumption is often made that incontinence is inevitable in older people, or those with dementia or other long-term conditions. However, research has highlighted strategies that can help them to retain continent.

A working group was established to develop a resource to promote continence for people with dementia and long-term conditions. This article explores the resource’s key messages, as well as the importance of changing how incontinence is viewed, and what health professionals and the public expect of continence services.

Incontinence is often accepted as an inevitable part of ageing. Although highly prevalent in Europe, the US and Canada, incontinence remains a largely “stigmatised and untreated condition” (Tannenbaum et al, 2013). This, compounded by the ways that care is delivered and continence issues often being accepted without a thorough assessment, means older people and those with dementia are sometimes not offered options of care but are resigned to a culture of “padding up” (Offermans et al, 2009). This can cause much distress, both for people with a dysfunctional bladder and/or bowel, and their families; the extra support needed is a key factor that often precipitates a move into residential care (Alzheimer Europe, 2014).

Nazarko (2012) suggests “understanding the older person’s difficulties and working with them can prevent a person becoming incontinent and make a huge difference to a person’s physical and mental wellbeing”. She also suggests that the design of the environment, access to help when it is requested, prescribed medication and the general culture of a service can all determine whether continence promotion is actively in place or not (Nazarko, 2013).

The fundamentals of achieving good continence-care outcomes can be summarised as five key points (Box 1). These are supported by Gibson and Wagg (2014), who state that continence requires: “...a functional lower urinary tract and pelvic floor, but also sufficient cognition to interpret the desire to void, and locate a toilet, adequate mobility and dexterity to allow safe and effective walking to the toilet, and an appropriate environment in which to allow this.”

The need for a continence resource

The Royal College of Physicians (2010) stated “people of all ages... continue to suffer unnecessarily and often in silence, with a life sentence of bladder and/or bowel incontinence”, while Booth (2013) said: “Continence is arguably the biggest threat to individual dignity, and the ability to maintain bladder and bowel continence is an elemental part of who we are.”

Unpublished data supplied in 2015 by National Services Scotland highlights that NHS Scotland currently spends approximately £12m every year on containment products alone (excluding delivery charges and urology services). However, problems with maintaining continence appear under-reported and underdiagnosed.

5 key points

1 Incontinence may be under-reported and underdiagnosed
2 Incontinence should not be seen as an inevitable part of the ageing process
3 Continence should be seen as the norm
4 With the right care, many people with continence problems can be helped to remain continent
5 The resource kit developed can help service users, staff and carers to reassess how they view incontinence

BOX 1. GOOD CONTINENCE-CARE OUTCOMES

- Recognise when people need to go to the toilet, and make sure they get there on time or help them find it
- Help them get to the toilet independently or with assistance
- Help them use the toilet once they get there
- Help them to adjust their clothing and wash their hands after they have used the toilet
- Help them find their way out and return to where they want to go
(Gibson and Wagg, 2014), suggesting that dignity, embarrassment, respect, effects relationships and wider societal issues need to be considered.

The Care Inspectorate (formerly Social Care and Social Work Improvement Scotland) is the regulation and improvement body for social care services in Scotland. It developed a resource that supports and builds on Booth’s (2013) view that dignity is compromised without appropriate continence care (Care Inspectorate, 2015). It was designed to:

- Give clear guidance on supporting people with continence problems;
- Challenge the belief that incontinence is an inevitable part of ageing;
- Highlight the importance of promoting continence across all sectors and linking it to the wellbeing of the whole person;
- Make the connection between assessment of bowel and bladder function, and how the provision of care can help maintain continence;
- Improve knowledge of care strategies;
- Highlight how an environment may promote or hinder continence;
- Practise the principles that promoting continence is everybody’s business;
- Highlight that each person with a continence issue is supported by an individualised plan of care;
- Make people think of promoting continence rather than managing incontinence;
- Highlight the importance of conducting a full lifestyle assessment after admission to longer-term care and on an ongoing basis;
- Highlight to all staff that how they communicate can affect individuals’ ability to remain continent;
- Challenge practice to come up with more creative approaches to help people remain continent – adopting the principle of always aiming for “cure”.

Data collected by the Care Inspectorate (April 2014 to March 2015) suggests a high prevalence of incontinence and product use in care homes for older people: during this period, 86% of care home residents in Scotland were incontinent and 80% of those were using containment products.

Using containment products is not necessarily wrong but they should be a last resort. Product use should not replace the need for planned, structured approaches to help residents to access toilet facilities.

The Care Inspectorate (2015) recognised that improving continence outcomes means viewing continence as the “norm” instead of emphasising incontinence through routine use of pads or catheters.

**Developing the resource**

About 90,000 people in Scotland have dementia (Alzheimer Scotland, 2015). More than one in three (440,000 out of 400,000) older people living at home, who find it difficult to go to the toilet, do not receive any help (Grigg, 2015).

A working group comprising a range of stakeholders (Fig 1) was established to explore research, review the findings from regulatory activity, and review the experiences and views of those with, or caring for someone with, a dysfunctional bladder and/or bowel who also has dementia.

The working group considered Fonda and Abrams’ (2006) model of continence (Fig 2), and explored potential barriers to delivering good continence care, for example, looking at how care is delivered, the environment, signage, the culture within the service and staff access to/uptake of competency-based continence training.

The group developed Promoting Continence for People Living with Dementia and Long-Term Conditions, which contains an easy-read guide, poster and DVD. It:

- Explores the fundamental care and support people need to have the chance to remain continent and maximise their quality of life;
- Asks care staff and the public to challenge their perception and assumptions of what it means to age;
- Encourages people not to see incontinence as an inevitable part of the ageing process.

The resource explores simple changes that may lead to better care outcomes and focuses on five key messages:

- Know me and what’s important in my life, and do what is best for me;
- Know me and how I communicate;
- What I need to stay continent and how you can help;
- Create an environment that supports me to be independent and promotes continence;
- Look for every opportunity to promote my continence – be creative.

Its underpinning message is that promoting continence is everybody’s business, while its focus is on improving outcomes and always aiming for “cure”.

The resource was piloted across a range of services including an NHS assessment unit, care homes, day centres and care-at-home in Scotland, and can be used across all sectors by people with continence problems, formal and informal carers, and health and social care staff. The aim of the pilot was to gain feedback from staff at service level about the proposed key messages prior to roll-out of the resource (see Box 2 for the outcomes).

Evidence suggests that many causes of incontinence can be identified and treated, and that continence in older people can be...
BOX 1. OUTCOMES OF THE RESOURCE
The Care Inspectorate anticipates that the roll-out and implementation of the resource will:
- Challenge expectations about ageing and/or living with dementia
- Promote the fundamentals of continence care, offering regular, planned access to toilet facilities as part of everyday living
- Put continence promotion and management at the centre of compassionate care
- Lead to widespread culture change with continence seen as the norm for older people and with care aiming to cure – and where cure is not possible, achieving the right outcome for the individual
- Help develop stronger links between individual services and local NHS continence advisory services, and other key stakeholders across Scotland, to achieve better continence-care outcomes
- Increase staff awareness about continence care and management to help improve outcomes for people living with dementia and long-term conditions
- Ensure carers and service users know what good continence care and management outcomes look like
- Reduce the numbers of people deemed incontinent
- Reduce the use of containment products and/or move to lower-absorbency products in some registered care services
- Reduce falls and urinary tract infections, and subsequent unplanned admissions to hospital

References
Alzheimer Europe (2014) 2014. Improving Continence Care for People with Dementia Living at Home. Bit.ly/AlzEurImprovingContCare


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Grigg L (2015) Over a Million Older People Struggling to Cope Alone. Bit.ly/AgeUKZeroCare


