Guidelines to improve the continence care of people with dementia living at home

Dianne Gove, Director for Projects, Alzheimer Europe
1. About the guidelines.

2. Why we need guidelines.

3. A brief overview of some of the key points from each section.
1. The development of the guidelines

Collaboration between SCA and Alzheimer Europe (extending over 2 years).

Consensus-based approach incorporating:

- Setting up of steering committee and working group
- Literature review
- Expert consultation
- Wider consultation
Members of the 2 groups

Steering committee:
• Mr Jean Georges
• Ms Nicole Huige
• Mr Ivar Næsheim
• Dr Paul van Houten

Working group
• Dr Dianne Gove
• Dr Daniela Hayder-Beichel
• Mr Kai Leichsenring
• Dr Vikky Morris
• Ms Helga Rohra
• Ms Breda Savage
• Mr Anthony Scerri
• Ms Willeke Sijkpes
The content of the guidelines

• Background information about dementia and continence problems

• Statements from people with dementia and carers

• The guidelines, covering:
  – Detection
  – Assessment (initial and specialist)
  – Management
2. Why we need guidelines

• Most people with dementia live at home (Wimo, Winblad and Jönsson, 2007).

• Incontinence and cognitive impairment in people with dementia may be a predictor for entry into residential care. (Forbat, 2004; Hope et al., 1998; Luppa et al., 2008; Phillipe et al., 2004).

• Little is known about the needs and care of people living at home who have dementia and incontinence (Drennan et al., 2012).
Needs and wishes of people with dementia

I need appropriate care, support and treatment for dementia & incontinence.

I would like to live independently and avoid being unnecessarily dependent.

I would appreciate a sensitive but pragmatic approach to continence issues and dementia.

I need appropriate care, support and treatment for dementia & incontinence.
Needs and wishes of informal carers

Providing continence care can be emotionally and psychologically disturbing.

I would appreciate recognition that I do not have nursing skills and have my own personal limits.

I would appreciate greater sensitivity from healthcare professionals.

I would appreciate recognition that I do not have nursing skills and have my own personal limits.
Background information

The intersection of continence, dementia and age

- Impact of drugs for incontinence and AD
- Difficulties with communication
- Difficulties understanding
- Difficulties with memory
- Difficulties with mobility
- Physiological changes
- Polypharmacy
- Co-morbidities

Continence

Dementia

Age
Dementia is not an inevitable consequence of ageing
(Fröhlich, 2008)

Incontinence is not an inevitable consequence of ageing
(Milsom et al., 2009)
3. The three main areas covered

Overriding principles

• a holistic perspective

• treatment and care options in accordance with national, European and/or international clinical guidelines on all related issues

• a care ethics perspective
Detection

Potential barriers to detection: normalization of incontinence and dementia, communication difficulties, lack of awareness, stigma and shame.

- Look for signs of incontinence.
- Ask about it.
- Be proactive.
- Contribute towards raising awareness
- Challenge the stigma of dementia and incontinence.
Assessment

• Non-discrimination
• Equity/justice
• Communication

• Supported decision-making (see Alzheimer Scotland’s guide “Dementia: making decisions” - 2012)
• Appropriate training

➢ Guidance provided on what to expect from the initial and specialist assessment
Management

Coordinated care plan (developed with people with dementia and carers)

Case coordinator or case manager with relevant expertise in both dementia and continence care

Step-wise approach (adapted to the individual)

Support for carers of people with dementia living at home must be part of any strategy to manage (in)continence.

Incontinence nurses/advisors and nurses specialised in incontinence care should be involved in the care of people with dementia and incontinence at home.
Continence care must be approached from a holistic perspective.

It must aim to improve the quality of life of people with dementia.

It must empower people with dementia and respect their dignity, integrity, wellbeing and autonomy.

It must provide informal carers with the support they need and respect their rights and needs.