

Continence management – advice for carers of people with dementia

Introduction

This information sheet is for carers of people with dementia. If the person with dementia has difficulties with continence there is a lot that can be done to help or even prevent the problem.

If you require further information about continence or other issues regarding dementia call the freephone Dementia Helpline on 0808 808 3000.

What is incontinence?

Incontinence is the loss of control of the bladder and/or bowel function. Our brains send messages to our bladder and bowel telling them when it is necessary to empty them. Being in control of these functions depends on an awareness of bodily sensations such as having a full bladder and knowing how, when and where to respond. When someone has dementia they may no longer be able to:

- recognise the need to go to the toilet
- be able to wait until it is appropriate to go to the toilet
- find the toilet
- recognise the toilet
- use the toilet properly.

Incontinence may happen frequently or the person may just experience occasional leakage.

It is common for people with dementia to do apparently 'odd' things, such as hide wet clothes or wrap faeces in parcels and hide them. This may be because they are embarrassed by what has happened and unable to think of a better way to deal with it.

Some people may urinate in inappropriate places such as the wastepaper basket, which they may have mistaken for the toilet. Removing objects from their room which could be mistaken for a toilet and ensuring they go to the toilet regularly may help. Try not to get angry or upset and remember they are behaving in this way because of the dementia.

Facts and figures

According to the Bladder and Bowel Foundation, approximately 60-70% of people with dementia develop incontinence. This is mostly urinary incontinence while bowel incontinence is not common until very late in the illness; but this varies from person to person.

It is rare for someone in the earlier stages of dementia to have continence problems. More often problems start as the dementia progresses from the moderate to severe stages.

Feelings

Personal hygiene is a very private issue

to all of us and many people find it hard to accept that they need help, even from someone very close to them. Respecting the privacy of the person with dementia and maintaining their dignity is very important. You will need to be tactful and sensitive when helping someone with personal hygiene.

For carers this problem can seem very frustrating, worrying, embarrassing or unpleasant. If you are finding it hard to cope with your feelings, talk with your community/district nurse or continence adviser.

People with dementia react differently to the experience of incontinence. Some find it very distressing and humiliating; other people appear to just accept it or are even unaware of it.

What can be done?

If the person becomes incontinent, don't just accept it as part of the illness. He or she may not be truly incontinent at all but may just have forgotten the way to the toilet or how to recognise it. Or he or she may not recognise the feeling of a full bladder.

The best solution is to seek advice and work out ways in which to manage the incontinence. In many cases the incontinence can be improved or even cured. Even when the problem does not clear up completely, there are many practical ways of coping with incontinence by using:

- aids such as pants and pads, or protective sheets on the bed
- equipment such as commodes, or hand held urinals
- services such as laundry services.

First step - consult your family doctor

There are many reasons why someone may experience loss of continence. These may or may not be associated with dementia, and the first step is to consult your GP or family doctor.

Information which will help the GP diagnose what is wrong

- How often is the person incontinent, is there a problem with urine and/or faecal incontinence and how often did they go to the toilet in a set period?
- When did the problem start?
- How severe is the problem; is there just a trickle or is the person saturated?
- Has there been any increase in confusion or any other changes in the person's behaviour?
- Has there been any fever or does the person appear to find it painful to go?
- Is the person on any medication?
- Does the person pass urine in any strange places, eg in a rubbish bin?

Treatable conditions

The first thing the GP will do is check to see if there's a physical/medical problem causing the incontinence. These could include:

- Urinary tract infections. This type of infection usually responds to treatment with antibiotics. Make sure the person is drinking enough fluids (6-8 glasses daily). Contrary to what you might expect, to drink less makes the problem worse. Urinary tract infections can increase confusion considerably, but this will get better after treatment.
- Constipation. This can be helped by changing the person's diet to include more food rich in fibre eg cereals, bread, fruit. Drinking plenty of fluids and keeping physically active will also help.

- Senile vaginitis (vaginal irritation after menopause), which can be treated.
- Prostate gland trouble. After assessment, the relevant medication will be recommended. If the medication does not work an operation may be advised.
- Reaction to drugs/medication. The GP may alter the dose or change the drugs.

Once the doctor has examined the person he or she will suggest treatments.

Finding help and support

The GP can refer the person to other professionals who can help.

- The community/district nurse can visit you at home and advise on how to manage the incontinence. He or she may be able to help with bladder training or pelvic floor exercises if appropriate. The community nurse will arrange the supply of pads and may organise a home bathing service.
- The continence advisor is a specialist nurse who can assess the person's condition and decide how best to treat it. He or she will be able to give you advice on how to manage the incontinence and what products will help.
- A hospital specialist such as an urologist, gynaecologist or geriatrician may carry out bladder tests and specialist treatments.
- A physiotherapist can teach pelvic floor exercises, if appropriate, and help to improve the person's mobility.
- An occupational therapist can advise on aids and equipment, which will help the person use the toilet. You can be referred to an occupational therapist through the social work department or the hospital specialist.
- In some areas there is a laundry service which will help you cope with the additional washing you may have to do. Ask the social work department, district

nurse or continence advisor if there is a laundry service in your area.

What you can do to help

If the doctor rules out any medical reasons for the incontinence then the cause is most likely to be the person's dementia. If this is the case there are ways in which to manage the incontinence to ensure that the person remains as independent as possible with as few accidents as possible.

Toileting routines

- Remind the person to go to the toilet or take them to the toilet at regular intervals.
- Monitor when the person is incontinent and try to work out the best times to take him or her to the toilet. This will usually be 15 to 20 minutes before the bladder needs to be emptied.
- Usually taking the person to the toilet before and after meals and before bedtime will help.
- Faecal incontinence can sometimes be managed by taking the person to the toilet at a set time, if their habits are regular.

Observing behaviour

- If the person is fidgeting, getting up or down or pulling at clothes it may be because he or she wants to go to the toilet.

Helping in the toilet

- If the person is having trouble urinating try giving him or her a glass of water or running the tap.
- If the person is restless and will not sit on the toilet, let him or her get up and down a few times. Music may have a calming effect or try providing something to hold or look at to distract the person while he or she is on the toilet.

Finding & using the toilet

- A 'toilet' sign or picture on the door of the bathroom will remind the person where it is - or leave the door to the bathroom open all the time, so that the person can see the toilet. If you use a sign, make sure it is in the person's line of vision and not too high or low on the door. Remember that pictures will be more helpful to some people with dementia, while others may find it easier to recognise words such as Toilet or Ladies or Gents. You may need to experiment to see what works best for the person you care for.
- Make sure that there are no obstacles in the person's way or doors which are hard to open.
- A clear path to the bathroom with suitable lighting day and night will help.
- Make sure that the toilet is easy to identify. Sometimes having the toilet seat a different colour to the toilet helps.
- Make sure the toilet is easy to use: perhaps handrails or raising the level of the toilet could help. An occupational therapist can advise on this.

Clothing

- If the person finds his or her clothes hard to remove or unfasten, try Velcro fastenings and elasticised waists.

Drinks

- Help the person to avoid having too much to drink before going to bed. However, ensure that he or she has had enough to drink during the day: 6-8 glasses. If someone doesn't drink enough, constipation or urinary infections could occur.
- The person should avoid too much caffeine such as coffee, tea and coca cola - caffeine can irritate the bladder and the person may need to urinate more urgently and more often.

Aids and equipment

- If it becomes too difficult for the person to get to the toilet a commode may be useful. Your community nurse will be able to advise you.

Hygiene and skin care

- Incontinence can lead to skin irritation and may make the person feel uncomfortable. If the person has become wet or soiled, help him or her to wash with mild soap and warm water and dry carefully before putting on fresh pads and clothes.
- You may need to use a simple barrier cream to help keep the person's skin dry (eg zinc or castor oil cream). This must be applied in a thin layer, especially if using incontinence pads, as the cream will affect how well the urine is absorbed by the pad. Do not use talcum powder.
- Put used pads in an appropriate container. Soiled clothes and sheets should be put in an airtight container until they can be washed.

Continence aids

Contact your community nurse or continence advisor for help and advice if you find that managing the incontinence is not enough and the person needs other help. There are products which will protect clothes, bedding and chairs. Some may be available through the continence advisor or community nurse, and you can buy others from a chemist.

Once you have the aids, pads and/or equipment, make sure they are suitable. The nurse will help you work out what suits the person best. If you are not happy with the products the person is using ask the nurse to come again and reassess the person to see what would be better. The nurse will also help you fit the pads properly, as incorrectly fitted pads are likely to leak.

Protecting furniture

You can protect the mattress with a waterproof cover, but make sure it does not come into contact with the person's skin, as it will cause soreness. You can also get special protective covers for duvets and pillows. Absorbent, reusable undersheets for chairs and beds enable the person to sit or lie on a dry surface.

Pads and pants

Contact your community nurse or continence advisor for an assessment, as they will be able to advise on the pads and pants which will best suit the person with dementia.

Special pads and pants can be worn, day and night or just during the night, which keep the area next to the person's skin dry. They come in a variety of sizes and shapes. Some are disposable and are held in place by close-fitting pants. Others are reusable, and often come as part of a pair of pants. All-in-one pads, with plastic backing and adhesive patches to seal the sides, are suitable for heavy incontinence.

These pads are usually provided free: ask your district/community nurse or continence advisor for information. It is important to make sure they are the right absorbency, that they do not chafe, and that they are changed as often as necessary.

Delivery service

Some areas have a delivery service which will bring the pads directly to your home. Ask your community nurse or continence advisor about this service. In other areas you may have to pick them up yourself. Carers have expressed concern over this, as the pads are heavy and bulky. Perhaps you could ask a friend to pick them up and bring them to your home for you.

Carer education and training courses

In some parts of the country, Alzheimer Scotland runs carer education courses which include specific sessions on how

to deal with incontinence. This is a very difficult problem to deal with on your own, but with support, advice and information life can be made a lot easier for the person with dementia and for you, the carer. Contact the Dementia Helpline or your local Alzheimer Scotland service for information on these courses. Your local Princess Royal Trust for Carers centre may also run a suitable course. The Dementia Helpline can tell you where your nearest centre is.

Costs of continence care

There could be some extra costs, such as protective bed sheets, laundry services, or even a new bed or mattress. If you do have to buy additional equipment or continence aids, find out if you can apply for funds to help with these costs. Below are a number of benefits you might be entitled to and what conditions you will need to meet in order to qualify for them.

It is always worth checking to see if there is help you could apply for. Seek advice to help you claim any of these benefits - ask the Citizens Advice Bureau (details in your local phone book).

Attendance Allowance and Disability Living Allowance

People who have personal care needs may be able to claim Attendance Allowance (AA) (if they are over 65), or the Care Component of Disability Living Allowance (DLA) (if they are under 65). Personal care includes help with toilet needs or managing continence.

People under 65 whose ability to walk is severely restricted because they experience severe discomfort may be able to receive the higher rate of mobility component of DLA. The term 'severe discomfort' can include incontinence brought on by the act of walking. Therefore, it is possible for someone who can only walk very short distances because walking induces incontinence to receive the higher rate mobility component.

AA and DLA are both tax-free non-means tested benefits and can be paid regardless of any other resources.

Community Care Grants from the Social Fund

People getting Pension Credit, Income Support, Income Based Jobseekers Allowance and Income Related Employment Support Allowance can apply to the Social Fund for Community Care Grants. Community Care Grants are intended to promote independent living in the community. They may help with additional costs such as a new bed, mattress, bedding, clothing, underwear and in some cases a washing machine, although a grant may be refused if the help is available from the National Health Service or elsewhere.

Community Care Grants are discretionary and there is no legal right to them. People who are refused a grant are often successful after challenging the decision through review procedures.

Severe Disability Premium and Enhanced Disability Premium

Some people who get AA or DLA may qualify for Severe Disability Premium or Enhanced Disability Premium as part of Pension Credit, Income Support, Income Based Jobseekers Allowance, Income Related Employment Support Allowance, Housing Benefit and Council Tax Benefit. These are paid to assist people with the increased costs of living with a disability. They are not paid specifically in connection with continence, but people with difficulty managing incontinence may receive a qualifying benefit which triggers these extra payments.

Free personal care

Personal care is free for people over 65 in Scotland, provided they are assessed as needing it. Contact your social work department for an assessment. Personal care includes help with:

- continence management – eg toileting, catheter/stoma care, skin care, extra laundry, bed changing
- personal hygiene – eg bathing, washing hair, shaving, oral hygiene, nail care.

For full details on free personal care contact the Dementia Helpline 0808 808 3000 for an information sheet or see the website www.alzscot.org

Don't try to cope alone

Carers often find it very hard to discuss continence issues, but knowing other people have faced the same problems and overcome them helps. Try not to let these problems get in the way of your relationship with the person with dementia. Talk to your GP, the community nurse or continence advisor. Another way to find out how to cope is by discussing this problem at carers' meetings, where you will be in a supportive group with other carers who understand what you are going through.

Having to provide intimate care in this way can be difficult, but remember there are ways to manage the incontinence – and support, help and advice are available.

More help

Bladder & Bowel Foundation
SATRA Innovation Park, Rockingham Road,
Kettering, Northants, NN16 9JH
Nurse helpline for medical advice: 0845
345 0165
Counsellor helpline: 0870 770 3246
Website: www.bladderandbowelfoundation.org

Continence Helpline: 0141 201 1861 (Monday – Friday 9am – 5pm). This is a confidential telephone service providing advice and information to the general public, carers and professionals.

Dementia Helpline: 0808 808 3000 (freephone, 24 hours). For confidential information and support on anything to do

with dementia, available 24 hours a day, 365 days of the year.

NHS Helpline : 0800 22 44 88 (8am to 10pm, every day). Information about health services and the NHS in Scotland, financial help, carers' groups and phone numbers for social services and local carers' organisations. Calls are free and confidential.

RADAR have a National Key Scheme which provides a key and list of toilets for disabled people, which can be particularly useful if you need to help the person with dementia in the toilet. For a key and list contact RADAR, 12 City Forum, 250 City Road, London, EC1V 8AF
Tel: 020 7250 3222
e-mail: radar@radar.org.uk; website: www.radar.org.uk



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