

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 our 24 hour Freephone Dementia Helpline on, **0808 808 3000**.

What is incontinence?

Incontinence is the loss of control of the bladder and/or bowel function. Our brain sends 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 only experience it occasionally.

It's a good idea to remove objects that could be mistaken for toilets, such as wastepaper baskets and try to encourage the person to go to the toilet regularly. If they find it difficult, or do have an accident, try not to get angry or upset. Remember, they are not doing it on purpose – it is a symptom of their condition.

Facts and figures

According to the Bladder and Bowel Foundation, approximately 60–70% of people with dementia develop incontinence. This is mostly urinary incontinence – bowel incontinence is not common until later on in the illness, though this can vary from person to person.

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

Feelings

Personal hygiene is a very private issue and it's natural that people may find it hard to accept if they need help. Tact and sensitivity are needed when tackling the subject – and it's very important that the person's privacy and dignity is always respected.

If you are a carer and are struggling with this issue, talk about your feelings with your community nurse or continence advisor. You may find it frustrating, worrying, embarrassing or unpleasant – but there is help available.

People with dementia react differently to the experience of incontinence. Some find it very distressing and humiliating, other people accept it or are 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 not recognise the feeling of a full bladder.

In many cases, incontinence can be improved – sometimes even cured – so it is best to seek advice as soon as possible. Even if the problem doesn't go away completely, there are many practical ways of coping with incontinence, such as 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 GP

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.

The doctor will ask a range of questions to help diagnose what is wrong, including:

- How often does the person experience incontinence?
- Is it urinary/bowel incontinence or both?
- How often have they been to the toilet in a set period?
- When did the problem start?
- How severe is the problem?
- 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?

Treatable conditions

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

- a urinary tract infection. This type of infection usually responds to antibiotics. Make sure the person is drinking enough fluids (6-8 glasses daily). Contrary to what you might expect, drinking less could make 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 appropriate 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 they will suggest appropriate 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 incontinence. They may be able to help with bladder training or pelvic floor exercises if appropriate. The community nurse will arrange a 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. They will be able to give you advice on how to manage incontinence and suggest products that might help.
- A hospital specialist such as a urologist, gynaecologist or geriatrician may carry out bladder tests and recommend 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 can help you cope with any 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 incontinence then the cause is most likely to be the person's dementia. If this is the case there are ways to manage so 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.
- 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 and down or pulling at clothes it may be because they want to go to the toilet.

Helping in the toilet

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

Finding and using the toilet

- A 'toilet' sign or picture on the door of the bathroom will remind the person where it is. Leaving the bathroom door open also means that the person will be able to see the toilet. If you use a sign, make sure it is in the person's line of sight and not too high or low on the door. Remember that pictures will be more helpful to some people, 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 that 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 their clothes hard to remove or unfasten, try Velcro fastenings and elasticised waists.

Drinks

- The person should avoid having too much to drink before they go to bed. However, it's important that they have had enough to drink during the day. It is recommended that we should all drink between 6-8 glasses each day. If the person isn't drinking enough, constipation or urinary tract infections are more likely to occur.
- It's sensible to avoid too much caffeine, such as coffee, tea and coca cola. Caffeine can irritate the bladder and make the person 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 they have become wet or soiled, help them 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 (e.g., 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 the person needs additional help. There are products available that can 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 show you how to 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 can 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. This will 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. Incontinence 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. Contact the Dementia Helpline or your local Alzheimer Scotland Centre for information on these courses. Your local Princess Royal Trust for Carers centre may also run a suitable course. Our 24 hour Freephone Dementia Helpline can tell you where your nearest centre is.

Costs of continence care

There could be some extra costs, such as for 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 details of eligibility.

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 (visit **www.cas.org.uk**).

Attendance Allowance and Disability Living Allowance

People living in Scotland who have personal care needs may be able to claim disability benefits to help with extra costs. Personal care includes help with toilet needs or managing continence. People over state retirement age can apply for Attendance Allowance or those who are under state retirement age can apply for the daily living component of Adult Disability Payment. *Note: Attendance Allowance is due to be replaced with Pension Age Disability Payment (PADP) over the course of 2025.

People under state retirement age whose ability to walk is severely restricted because they experience severe discomfort may also be able to apply for the mobility component of Adult Disability Payment. 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 an award of the mobility component.

Attendance Allowance and Adult Disability Payment are both tax-free, non-means tested benefits. This means that your eligibility is based on your needs and is not dependent on your income, savings or assets.

Community Care Grants from the Social Fund

Community Care Grants are intended to promote independent living in the community. They can 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.

People on a low income, such as those in receipt of Pension Credit, Income Support, income-based Jobseeker's Allowance (JSA), income-based Employment and Support Allowance (ESA) or Universal Credit, can apply to their local authority for a Community Care Grant. If you have savings of over £700, or £1,200 if you get a pension, you'll be less likely to get a Community Care Grant. Your local council will decide if you qualify for a grant.

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 our Freephone Dementia Helpline **0808 808 3000** for an information sheet or visit our website at **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 have overcome them can help. 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 can be difficult, but remember there are ways to manage incontinence – and support, help and advice are available.

More help

Bladder & Bowel Foundation:

Tel: 0800 031 5406

Nurse helpline for medical advice: 0845 345 0165

Counsellor helpline: 0870 770 3246

Forward House, 17 High Street, Henley-in-Arden, B95 5AA

Website: www.bladderandbowelfoundation.org

Continence Helpline:

Tel: 0141 201 1861 (Monday – Friday 9am – 5pm).

This is a confidential telephone service providing advice and information to the general public, carers and professionals.

Alzheimer Scotland 24 hour Freephone Dementia Helpline:

Tel: 0808 808 3000

For confidential information and support on anything to do with dementia, available 24 hours a day, 365 days of the year.

NHS:

Tel: 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:

Tel: 01395 222588

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, 11 Church Street, Exmouth, Devon EX8 1PE

E-mail: radar@radar.org.uk

Website: www.radarkey.org