

# A time to care, a time to care for yourself

A guide for carers looking after a person experiencing bladder weakness and incontinence





## Introduction

Many of the population over the age of 65 may need other people's help to lead a normal life. The causes of dependency can be many and varied, including:

- Mental deterioration, e.g. memory loss, neurological illness, dementia.
- Physical limitations, e.g. reduced mobility, stroke, Parkinson's disease.
- Sensory problems, e.g. blindness, deafness, etc.
- Health problems, both long and short term.

Some elderly people receive help in their own homes with ongoing and intensive care provided by their family members or friends. We have put this guide together for non-professional carers like you, who look after a dependent person or who may have to do so in the near future.

We hope this guide helps you by providing sensible, practical and useful advice on caring for others, along with some healthy suggestions for you as the carer, so you can meet the needs of those you care for without compromising your own needs.



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# Part 1: Learning to care for others

# When does a person start being a carer?

In most cases, people do not become carers overnight – it takes time to adjust to the fact that a person depends on you in his or her daily life. This means coming to terms with a person needing care and supervision.

Carers are people like you (e.g. parents, children, family members, friends, neighbours and volunteers) or associations, profit or non-profit, who take care of dependent people.

### What is dependency?

A person is considered dependent when he or she needs almost constant care from someone else, or when he or she needs material aids (such as a wheelchair) in order to perform basic activities in his or her daily life. For example, walking, getting dressed, eating, socialising, accessing goods and services like basic shopping, and so on.

### Adapting your home

Your dependent family member or friend will spend most of his or her time in the home, so it may need to be adapted to provide a safe, comfortable environment.

- Look at access throughout the home, both inside and out.
- Make sure floors have a dry non-slip surface and avoid rugs.
- Ensure that there is enough lighting and ventilation and that light switches are easily accessible.
- Fit protectors for sockets, radiators and staircases.
- Adapt any fixtures and furniture as needed, for example, lowering kitchen work tops, modifying the bathroom to include a walk-in shower and raised toilet seat.
- Where possible, the cooker should be electric.
- Try to avoid any objects that can be broken or splintered, e.g. mirrors or glass, or anything that is toxic, such as bleach.



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### Part 1: Learning to care for others

### How to promote mobility

If the person you are caring for is not fully mobile, you can follow these tips to assist them in finding their way around.

- Try to provide a safe and familiar environment.
- Place signs with pictures on doors and in their room and use easily identifiable objects such as calendars and large clocks to help guide them.
- Remove any potential obstacles that may cause them to fall.
- Make any necessary modifications to support their daily activities.
- Encourage them to carry out gentle exercise. You do not have to be fully mobile to benefit exercises can be done sitting down.
- Change their position from time to time if they are unable to move themselves.

### Manage wandering

At some point, the person you are caring for may begin to wander. There are a number of reasons why this might happen – but the person's failing memory and declining ability to communicate may make it impossible for them to remember or explain.

- A physical check-up will help identify whether illness, pain or discomfort has triggered the wandering.
- Try to avoid medication where possible as it may increase confusion and cause drowsiness. Talk to your doctor about the side effects of any medication taken by the person you are caring for.
- Some people find it helpful to keep a diary so they can see if there is a pattern to the wandering behaviour. It may happen at certain times of the day or in particular situations which can then be more carefully controlled.
- Sometimes it is enough to move door locks to positions where the person will not think to look for them.
- Consider installing bells or buzzers that sound when external doors are opened.
- Make part of the garden secure so it becomes a safe place to walk around.
- Tell neighbours and local shopkeepers. Most people will be very understanding and supportive.
- Make sure the person carries some form of identification in case they do get lost. An identity bracelet with their name, address and your telephone number is probably the most sensible. Or you could try a MedicAlert<sup>®</sup> bracelet with a telephone number.
- Keep a recent photograph of the person you are caring for. It could prove useful if they do get lost and you need to show the picture around to find them.



### **Getting dressed**

- Make sure the person's clothing and shoes fit well and are comfortable.
- Choose clothing that is easy to put on and handle.
- Allow time for the person you care for to dress themselves as much as they can.
- Try to only help when it is needed.

### **Dietary advice**

In this section we will focus on dependent people who do not have any difficulty ingesting food orally, given that this applies in most cases. Some patients may need to be fed through a tube – you will need training or the help of a qualified professional for advice relating to this type of feeding.

### Meals

- Allow the person as much time as they need to eat by themselves.
- Make sure they drink enough water dehydration increases the chance of confusion.
- Try to establish regular schedules and routines.
- Make sure the dependent person eats a varied diet that suits their particular circumstances.

### Part 1: Learning to care for others

### **Promoting sleep**

Sleep problems are common among older people. Some people sleep during the day and are awake at night, while others are simply not as active as they used to be and therefore need less sleep. If the person you are caring for has trouble sleeping, here are a few suggestions:

- Create a suitable environment used exclusively for sleeping. Make sure it's well ventilated, calm and free of noise.
- Try to maintain regular bedtime hours.
- Encourage the person to exercise whenever possible and to keep busy and active during the day.
- Encourage them to perform relaxing exercises before bed.
- Try to minimise sleeping during the day no more than a short nap of 30-45 minutes maximum.
- Avoid heavy meals before bed.



### Coping with behavioural changes

The person you are caring for may behave in different ways at different times – for example moving from sadness and apathy to anger.

### Dealing with sadness and inactivity

- Make the person you are caring for feel involved and active, encouraging them to join in activities they enjoy.
- Try to fill their free time with things they like to do.
- Encourage them to participate in groups and associations, building friendships with other people.
- Never insist or pressure them into doing something give them time.
- Stimulate and maintain the person's interest as much as possible.
- Pay attention to them, give praise and show the pleasure you feel when they communicate with you.

### Dealing with anger and rage

- Never use medication to calm the person you are caring for, unless it has been prescribed by a specialist.
- If their behaviour becomes difficult, do not attempt physical contact, such as restraining the person, leading them away or approaching them from behind. Leave them alone until they have calmed down, or call a friend or neighbour for support.
- Approach the person slowly and in full view if it is safe to do so. Always give an explanation of your actions, i.e. I'm going to help you take your coat off now.
- Ignore their aggressive behaviour and explain that it does not mean they will get what they want.
- Don't take it personally and try to stay detached do not allow yourself to be provoked or drawn into an argument.
- Try to remain calm and do not raise your voice. Speak slowly in a soothing and reassuring way.
- Avoid punishing the person you are caring for. They may not remember the episode once it has happened so they may not be able to learn from it.
- Be aware that certain health problems, such as pain or fever can trigger behavioural changes.
- Try not to give in to unwarranted demands or it will be more difficult to say no next time.

### Part 1: Learning to care for others

### Assisting with personal hygiene

Personal hygiene (bathing, showering etc) is often one of the first daily activities to be affected when a person begins to have difficulty being independent. It is an essential part of caring for a dependent person and the attention and respect you show them is extremely important in their daily lives.

## What you should know about daily personal hygiene

#### During the day:

If the person can stand or sit in a shower chair, you can give them a bath or shower, aiming to wash their hair at least once a week. For very dependent people, wash them in bed.

Remember that washing and dressing are intimate, private activities. Many people may be embarrassed or humiliated by their need for assistance, especially if they experience incontinence or bladder weakness. They may even refuse to bath or change their clothes to try to disguise the problem.

In addition, the person you are caring for may not be used to bathing or showering daily – in the past, many people did not bath as often as they do today. Make sure you do not impose your own values about how often they should bath.

Choose the best time of day for bathing, preferably matching the person's routine prior to them needing your support. When are they most relaxed and do they prefer to have a bath, shower or sponge bath?

## Changing absorbent products (if the person you are caring for experiences bladder weakness or incontinence):

Although you can schedule regular changes, we recommend you change the person's pad when it is full, as shown by the wetness indicator included on some bladder weakness and incontinence products.

#### Night-time hygiene:

As a minimum, clean the person's hands and face before helping them to bed.



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# Part 2: How to deal with incontinence

### Urinary incontinence

### What is it?

Urinary incontinence (UI) is the involuntary loss of urine at an inappropriate time and place and in a quantity and frequency that is sufficient to cause a problem to the person that experiences it. It can also limit the activeness of the person and their social relationships. It can occur at any age and in both men and women, however, it is more common in women over 60. Among the population, the incidence of incontinence is 1 in 4 (24%)\* for women over 65 and 1 in 7 (15%)\* for men.

### Types of urinary incontinence

### **Stress Incontinence**

This incontinence is the most common type of female urinary incontinence. It occurs following the weakening of the muscles of the pelvic floor that support the bladder. Other factors that may cause this include menopause, being overweight and pregnancy. It can happen following exertion, coughing etc.

#### **Urge Incontinence**

This type of incontinence is also known as overactive bladder. It occurs when a person has a strong, urgent need to urinate and the bladder involuntarily expels urine. The main causes of this type of UI include neurological problems or lesions, inflammation of the bladder, infections etc.

#### **Mixed Incontinence**

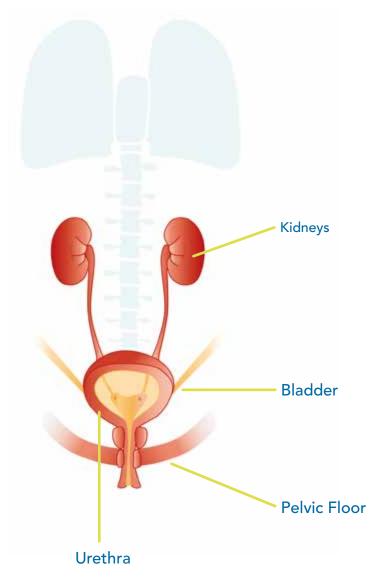
Some people, mostly women, have mixed incontinence. It is a mixture of stress and urge incontinence. If you experience both types of urinary loss you may notice that one type occurs more than the other.

Other physical or mental problems can prevent a person reaching the toilet in time, such as being unable to respond suitably to the sensation of needing to urinate, due to a physical or mental incapacity.

In the daily care of a dependent family member, particularly the elderly, we may be looking at situations related to:

• Urinary incontinence and/or

• Faecal incontinence





### Faecal incontinence

### What is it?

Faecal incontinence (FI) can be defined as a person's inability to voluntarily control the anal sphincter, leading to the involuntary expulsion of faeces and gases.

### Who experiences it?

It happens more frequently to women that have given birth vaginally, the elderly and people who have experienced trauma (such as an accident), people who have undergone major surgery, or who have experienced apoplexy (a sudden inability to feel or move). Some diseases like diabetes or Parkinson's can cause intestinal problems and people with inflammatory bowel disease or irritable bowel syndrome may feel an urgent need to go to the toilet or experience some loss of control.

### Why does it occur?

Faecal incontinence has many possible causes.

- Constipation leading to debilitation of the anus and bowels.
- Impaction of the faeces in the rectum.
- Serious diarrhoea.
- Lesions to the anal sphincter muscle.
- Lesions to the nerves or other muscles.
- Rectal, prostate or gynaecological surgery.
- Over use of laxatives.

### How to treat it - changing your lifestyle

Changes to the person's diet can help greatly – try eliminating alcohol and caffeine and increasing fibre intake to increase the amount of faeces. The bladder can also be retrained to help improve muscle tone.

A GP or Continence Advisor should be able to offer useful advice and a GP may also be able to prescribe drugs such as loperamide to control diarrhoea and possibly eliminate incontinence. If there is a clearly identifiable cause, surgery may even be an option.

# Improving the quality of life for people experiencing incontinence

If you are caring for someone experiencing incontinence, here are a few ways you could help improve their quality of life:

- Encourage open discussion of the condition and offer solutions recommended by a professional.
- Use technical aids, such as handrails, an elevated toilet, bedpan, etc.
- Plan an appropriate diet and fluid intake.
- Create a daily routine for them.
- Make sure this routine includes regular personal hygiene care.
- If the person is unable to go to the toilet on their own, help them do this several times each day and before their bedtime.
- Make sure they receive a professional assessment for the right incontinent product for the dependent person's particular needs.

### Skin care for people with incontinence

People who experience urinary or faecal incontinence run a greater risk of skin irritation problems, given that using pads creates a humid and closed environment. This humidity makes the skin fragile and more sensitive to friction and sores. Here are a few suggestions to help you prevent this:

- Change the pad when the wetness indicator has turned <sup>2</sup>/<sub>3</sub> blue or as soon as it contains faeces.
- Wash the skin gently with water and a mild soap before drying it thoroughly.
- Frequent skin cleansing can cause dryness and irritation so use a moisturising cream where necessary to maintain moisture levels.
- Avoid products containing alcohol as they can further irritate the skin.
- These days, '3 in 1' skin hygiene products are available. They are specifically designed to clean and deodorise skin and do not need rinsing, avoiding excessive dryness and irritation.

### Part 2: How to deal with incontinence





TENA *Flex* is a next-generation product. It is comfortable and simple to use, with an easy close and open belt system designed to help you, the carer. 100% breathable, it allows air to circulate over the entire surface – and the unique TENA *FeelDry*<sup>™</sup> System offers extraordinary dryness through quick absorption and excellent retention.



### **TENA** Pants

TENA *Pants* are the first absorbent undergarment to keep skin dry for longer while allowing complete freedom of movement. TENA *Pants* are discreet, with a unique *Odour Neutraliser*<sup>™</sup> system that stops unwanted odours forming. As with the TENA *Flex* they are 100% breathable, offering comfort and increasing the sense of freshness for the wearer. You can put TENA *Pants* on like normal underwear and once used, they can easily be torn down from the sides for easy removal.



These small, slim reliable pads in three absorbencies have an extremely effective inner core, allowing faster fluid acquisition and improved absorbency keeping the skin dry and the user secure. The adhesive strip on the back secures the pad in position within normal underwear. The unique Odour Control<sup>™</sup> feature inhibits the development of embarrassing smells for a more dignified way of life.



### **TENA** Slip

For those who require or prefer an all-in-one product, TENA *Slip* offers increased absorption and leakage security in three levels and four sizes to meet individual requirements. TENA *Slip* has a *FeelDry*<sup>™</sup> layer that provides outstanding dryness and leakage security.



### **TENA** *Fix* **Premium**

To be used in conjunction with body-worn pads, these reusable stretch pants come in six sizes. They have been developed to last longer and to hold both shape and elasticity even with frequent laundering. TENA *Fix* Premium has no side seams. With no pressure point, wearers are assured comfort which helps avoid skin chafing and irritation. TENA *Fix* Premium also offers a stable and secure fixation of TENA Comfort products.

















### How to deal with incontinence

The incidence of incontinence increases with age and has various causes. Despite the large number of people that experience incontinence problems, it still remains a taboo that can affect a person's social life, however there are things you can do to help improve their quality of life and reduce the impact of this condition:

- Using absorbent products, such as pads and pants, can offer increased levels of freedom.
- Good daily hygiene and skincare is important.
- As well as choosing the right size and absorbency of products, make sure the person you are caring for uses products that specifically care for skin in the perineal area (the area between the anus and the scrotum or vulva).

Whatever incontinence problems the person you care for experiences, ask their doctor or specialist for advice on diagnosing the causes so you can find the best solution together.



### Part 3: Learning to care for yourself

# Part 3: Learning to care for yourself

### Caring for the carer

We have looked at the potential consequences of caring for a dependent person but it is important to recognise the signs that you are not coping as well as you were, so you can make a few changes and take some of the pressure off. A carer or someone close to them should always be looking out for the following:

- Loss of energy, constant tiredness, sleepiness.
- Isolation.
- Increased consumption of alcohol, smoking or prescription drugs.
- Memory loss, difficulty concentrating, low productivity.
- Decreased interest in activities and people.
- Increase or decrease in appetite.
- Frequent mood swings, irritability, nervousness.
- Treating other people less considerately than usual.
- Problems at work or with finances.
- Less affection and interest towards the person being cared for, or even contemptuous treatment of them.

These physical and mental problems can all arise from a prolonged period of caring for someone. If you are at all concerned, seek help.

### Learn to care for yourself

Caring for someone can mean can mean re-organising family, work and your social life to fit around the tasks you need to carry out. The impact of these circumstances varies enormously, depending on the characteristics, problems or illnesses that the person experiences, how far along their illness is, their mental well-being, etc.

It is crucial to ask for help when you are a carer. Do not try to take on all the responsibility by yourself. Asking for help is not always easy but it is important.

### But how do you ask for help from others?

- If you need help, ask for it openly.
- If you can, be clear about the type of help you need if you can.
- Remember that asking for help is not a sign of weakness but an excellent way of caring for yourself so you are better able to care for your friend or family member.
- Learn to accept help and gain knowledge from other family members, institutions, organisations and associations, adapting the support they offer you to your circumstances.
- Experts may be able to provide additional assistance.
- Avoid thinking 'no-one can care better than me' or you will be unlikely to ask for enough help.

### Part 3: Learning to care for yourself

#### Lead a healthy life

Carers who feel good are those who maintain healthy habits that help them stay in top physical and psychological condition, so they also care for themselves.

- Exercise regularly.
- Avoid isolating yourself.
- Maintain your hobbies and interests.
- Make time for the rest of your family.
- Get enough rest.

#### Exercise regularly

Physical exercise is a great way to combat emotional stress. It will help you get rid of any frustration you may have built up over the day.

#### Get enough sleep

Sleep is absolutely essential. Lack of sleep is common among carers because they often have to take care of a family member during the night. This can then increase emotional stress and lead to even greater fatigue. If you have not been able to rest sufficiently during the night, try to take some time during the day instead.

#### Avoid isolating yourself

Carers often distance themselves from their friends and family when the person they are caring for needs intense dedication – it can cause you to feel overloaded and stressed and can lead to physical and psychological problems. Make sure you set aside some free time to spend relaxing with friends.



#### Maintain your hobbies and interests

It is easy for carers to focus exclusively on the needs of the person they care for and to neglect themselves, so it is important to maintain a balance, allowing time for yourself. If you have abandoned hobbies you previously enjoyed, try to gradually incorporate these back into your life.

#### Make time for the rest of your family

Be careful not to neglect the rest of your family. Try to plan 'shifts' with other family members.

#### Get enough rest

People like you who are caring for someone can spend a lot of the day exerting themselves – which is why it is important to rest every day without leaving the person you are caring for on their own. In most cases it is easy to find a few minutes to take a breather and relax, as long as you organise your time well.

Trying to organise your obligations, needs and the amount of hours you have available will help you make better use of your time, enjoying a better quality of life as a carer.

#### How to organise your time

- Before you do anything, ask yourself if it really needs to be done decide which activities are important and which ones you can say no to.
- Always set realistic goals and never expect too much of yourself.
- Draw up a plan of activities and tasks.
- Ask other family members to help and include this help in your plan.
- Let the person you are caring for know that some responsibilities will be carried out by other family members and not by you.
- Don't be afraid to limit the amount of care you offer depending on the abilities of the person you are caring for, otherwise they may start to feel even less able.
- Although it may be difficult, learn to say no.

# How do you know when you may need to limit the care you offer?

When the person you are caring for:

- Blames you, the carer, for mistakes that he or she makes involuntarily.
- Fakes symptoms to receive more attention.
- Reproaches you when you place reasonable limits on the care you are giving.
- Blames others for problems he or she has caused themselves.
- Refuses help that will make your life easier, such as a wheelchair.
- Becomes aggressive towards you or pushes/hits you.
- Refuses to spend his or her money on necessary services such as hiring someone to help with their care.
- Asks for more help than they really need.

### Consequences of care on the carer

Caring for a loved one can be comforting and positive at times but it is important to remember that you are not a professional carer so it can affect other areas of your life, such as your family relationships, work and financial situation, free time, health and well-being.

### The satisfaction of caring for others

Sometimes carers find they possess qualities they did not know they had. Many of them say they developed new strengths through situations associated with care. There are also other advantages for the carer looking after someone, in addition to the quality of care they give the dependent person and the improvement in the persons living conditions:

- It brings people together and creates a tighter bond.
- It causes people to value the time they spend together.
- It helps carers improve their organisational skills and learn to multi-task.
- It can help carers expand their own values.
- It increases carers sense of compassion and caring.
- It can help carers plan their own future.

### Changes in your life

### Changes in family relations

On occasion, conflicts can arise within the family due to disagreements over people's involvement in the care of the dependent person.

### Mood swings

As the primary carer, you may experience many emotions. Some of them will be positive, like the feelings of satisfaction thanks to the improvement in the person you care for's quality of life. But these emotional changes can also be negative, with feelings of inability, guilt or loneliness. Keep in mind that help is available if things get too much for you – in the form of patients' associations, social services, your own family or even a psychologist.

### Changes to your health

Caring over the long-term can affect your health. You may often feel tired or suspect that your health is deteriorating. If you do notice any worrying changes, see your doctor.

### Feelings of guilt

At some point you may be faced with a very difficult decision – whether or not you should place the person you are caring for in a care home. If you do decide to go ahead, you will be free of some of your current worries but will also find yourself facing some new ones, such as concerns about the attention they will receive, the costs involved, feelings of guilt, what people will say, etc.

You should not make the decision on your own. Talk to all the family members involved and, if necessary, ask relevant charities, associations and medical professionals for their opinions.

Once the person you care for is in a home, remember that they will be receiving the best possible care.

66 My father's incapacitation... has reached a point where we have no choice but to find him a care home. However, I haven't got the courage to make the decision. I feel like I'll be abandoning him.99

## Part 3: Learning to care for yourself

### Where to get help

Although family and friends can provide you with valuable help, sometimes this is not enough and it is time to bring in the professionals. Your local authority is a good place to start looking for support and local services. All councils have websites showing what is available in each area.

Visit **www.direct.gov.uk** if you do not know your local authority, or for information on carers' allowances, a guide to other financial support that may be available, plus a range of practical information on caring for a dependent person.

You may find that not all the help offered by the local authority through social services is actually provided by them. Social services often work with other agencies, such as charities or private sector organisations.

If you do not have access to the internet, you can find local addresses and phone numbers by calling a telephone directory service. The notice board in your local library may also have information on support groups in your area. You could also contact your surgery or local health centre.

#### In summary

- Carers must learn to care for themselves in order to care for others.
- Learn to ask for help or you may not receive any assistance.
- Make time for yourself.
- Get enough sleep.
- Take regular exercise.
- Keep in touch with friends.
- Allow time for hobbies and interests.
- Organise your time.
- Place limits on the help you provide.

I'm single...and my parents depend on me. My brothers are grateful to me for taking care of our parents and give me their moral support, but when it comes to helping out, they're never available. Wouldn't it be fairer if we all shared the responsibilities? 99

### Some useful contacts

Here are a few of the contacts available to you.

#### Age UK (Combining Age Concern and Help the Aged)

Provide assistance on all aspects of aging and on carer support. There are local branches around the country – just call the number below to find your nearest one. Age UK has a free e-newsletter which you can subscribe to. Telephone: 0800 169 6565. Website: www.ageuk.org.uk

#### **Alzheimer's Society**

A society which works to improve the quality of life of people affected by dementia. There is a free e-newsletter available. Call the number below for more information about local groups.

Alzheimer's Society Devon House 58 St Katherine's Way London E1W 1JX

Telephone: 020 7423 3500 Email: enquiries@alzheimers.org.uk Website: www.alzheimers.org.uk

#### Carers UK

Carers UK provides carers, those supporting them and others with national and local information about benefits they are entitled to.

Carers UK 20 Great Dover Street London SE1 4LX

Telephone: 020 7378 4999 Email: info@carersuk.org Website: www.carersuk.org

#### Crossroads - Caring for Carers

Crossroads provides practical help and support, usually in the home, through trained Carer Support Workers.

Telephone: 0845 450 0350 Website: www.crossroadscare.org.uk

### Carers Line

Telephone: 0808 808 7777 Wednesday and Thursday 10am – 12pm and 2pm – 4pm

#### **Counsel and Care**

Charity giving advice and information to older people, their relatives and carers across the UK.

Advice Line: 0845 300 7585 Email: advice@counselandcare.org.uk

#### **NHS Choices Carers Direct**

Free, confidential information and advice for carers. Lines are open 8am to 9pm Monday to Friday, 11am to 4pm at weekends. Calls are free from UK landlines or you can request a free call back.

Telephone: 0808 802 0202

#### The Princess Royal Trust for Carers

The Princess Royal Trust for Carers provides advice and support services to carers of all ages through a network of independently managed Carers Centres, young carer services and interactive websites.

The Princess Royal Trust for Carers Unit 14, Bourne Court Southend Road Woodford Green Essex IG8 8HD

Telephone: 0844 800 4361 Fax: 0844 800 4362 Email: info@carers.org Website: www.carers.org



#### **Incontinence** Choice

Incontinence products direct to trade and public. Incontinence pants, incontinence pads and bed pads.

Telephone: 01952 913112 Website: www.incontinencechoice.co.uk

## Recognition

SCA was named one of the world's most ethical companies by the Ethisphere Institute, USA

SCA is included in Dow Jones Sustainability Index

In WWF's Environmental Paper Evaluation, SCA scored highest both in the tissue and containerboard categories

SCA has been listed on the FTSE4Good global sustainability index since 2001

SCA is included in the Carbon Disclosure Leadership Index

SCA is a signatory of the UN Global Compact

SCA is a member of World Business Council for Sustainable Development

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