

A booklet about dementia
for families and carers of a
person with Down's syndrome.



Down's
Syndrome
Scotland

helping people realise their potential

Living with dementia



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People with dementia will be affected by changes in behaviour at different stages of their illness.

This book explores the possible reasons for these changes, gives an insight into how dementia is experienced by people with Down's syndrome and provides potential solutions.

There are different types of dementia with each affecting a different part of the brain. This is why people do not all follow the same pattern when they have dementia.

Knowing the form of dementia that the person you care for has been diagnosed with can help you to understand the changes that are happening. Ask for a specific diagnosis and be aware that some people may have more than one form of dementia at the same time.

Examples of some different forms of dementia:

Fronto-temporal dementia	The part of the brain affected may change behaviour, personality, emotions and language.
Alzheimer's disease	The part of the brain affected may change memory, word finding ability, confidence and mood.
Vascular dementia	The part of the brain affected may cause depression, risk of strokes, confusion, often seen with a 'stepped' effect and sudden deterioration.
Dementia with Lewy bodies	The part of the brain affected may change communication, memory, hallucinations, day/night routines and muscle stiffness. People who have dementia with Lewy bodies may react badly to some medication.

“ *I didn't know people with Down's syndrome were prone to dementia until Joe was diagnosed. Make sure you get information about dementia early on, so you know what to expect.”*
- Liz

Household environment

Living Area

Potential issue

- Not wanting to go into a room that has previously been well used

Ideas to try

- Check the décor to make sure that colours are plain, not too patterned.
Create a contrasting colour between the wall and floor with strong but calming colours.
- Close the curtains and blinds when it is dark. Reflective glare from windows at night can be disturbing and may have the effect of a mirror.
- Turn down the volume on the television or radio before changing the channel to avoid sudden noises. Too much noise can be distressing, although quiet music may be soothing if it is an appropriate style of music for the person.
- Include additional lighting on stairs and in bathrooms. Make sure there is a shade on lights and lamps, not just bare bulbs. In winter months put lamps on before the light fades.
- Make the room safer by removing unneeded items of furniture. Spatial awareness may be affected and people may bump into furniture if they have difficulty in judging distances.



***Adding a small light will make living areas safer.
Shadows can be confusing and distressing.***

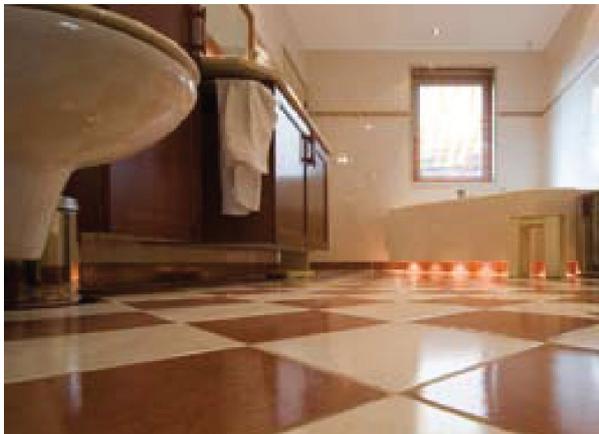
Bathroom

Potential issues

- Refusing to have a shower
- Not using the toilet or bath appropriately
- Not wanting to enter the bathroom

Ideas to try

- Remove or cover the bathroom mirror. People with dementia may not recognise themselves in the mirror. It may appear as if an intruder is in the room, causing fear.
- If a female carer is wearing trousers, try wearing a skirt. Due to a difficulty in perception, a person wearing trousers may be seen as male. This may cause embarrassment and distress for females when intimate care is needed.
- Cover the floor, or if it can be changed opt for a dull colour. Put mats around the outside of a shower cubicle as a white shower on a white floor with white tiles will become lost to a person with dementia. A shiny bathroom floor can look like water, just as a dark floor may look like a hole.
- Non patterned, non slip and non gloss flooring, in a colour that contrasts with the wall, will help the person to enter and find their way around the room.
- Replace shower doors or cubicle with a curtain. This will allow for easier access and for help should it be needed.



Light reflected in this bathroom gives the impression of water. The perception of a person with dementia can be the same as the picture on the right when entering a new room.

- Offer a bath instead. A person with Down's syndrome and dementia may have grown up taking a bath rather than a shower, therefore a shower will seem alien and frightening. A bath may be preferred even if immediately prior to their illness the person used the shower.
- Avoid white toilet seats, instead use a seat in a contrasting colour to the toilet to help with identification.



A toilet or bath may not be seen or used appropriately if the bathroom is white.



Adding colour as shown here makes the toilet easier to see.

- Colour the water in the toilet bowl to help men with their aim.
- The type of flush used on the toilet and taps on the sink or bath may mean that that they are not recognised. Modern push button flushes may not be familiar to a person with dementia, so will not be used. Change door handles and taps to a style that the person may have been previously used to. Lever taps for example may not be recognised or used appropriately.
- Leaving the toilet door open when not in use may be a reminder of the function of the room.
- Use a clear pictorial sign on the door labelling the bathroom/toilet



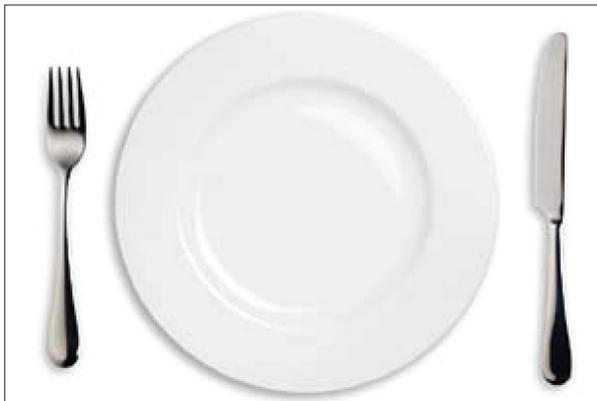
Eating

Potential issues

- Becoming upset at mealtimes
- Eating from the table rather than a plate
- Refusing to eat food or eating very slowly

Ideas to try

- Restrict noise, choice and conversation. Too many different sights, sounds, smells and movements may cause confusion and can result in distress. Try not to have too many conversations going on at the same time.
- Watch the person's body language to see if they have eaten enough, don't like the food or are in pain. Many people with dementia will forget that they have eaten or confuse the time of day.
- Keep a specific area for eating, if possible. Try to include the person with Down's syndrome in preparing the food. This can help reinforce that it is to be eaten at that time.
- Soft or liquidised food may be easier to eat. It is important that each item of food is still presented separately, not all blended together.
- Use a plain coloured table or tablecloth, with a different plain coloured plate. There may be a difficulty in recognising a difference between colours and textures, patterns can be especially confusing meaning that the food does not become visible on the plate.



This shows how a white plate may become lost against a white table or cloth. By adding a coloured background the plate is easier to identify.



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By adding a coloured background the plate is easier to identify.

- Keep non-perishable finger food available around the house for snacks and nutrition between meals.
- Don't rush mealtimes, instead treat them as a social event. Music may be played if this interests the person.
- Make sure false teeth are well fitting.
- Use a cup rather than a mug for drinking if this is what the person used when they were younger. Food needs to be appropriate for a person who has poor short term memory but maintains some long term memory. In earlier years they may not have eaten potato wedges for example, so will not recognise this kind of food now. Appliances must be meaningful, for example a person with dementia may not recognise pop up toasters, cookers, microwaves, or jug style kettles.
- Make sure out of date food is thrown away.
- Doors may be removed from some cupboards or labelled with pictures or photographs to show what is inside. Clear information about what is in the cupboard can make it easier to find things and support independence.
- Being thirsty can cause dehydration and can then lead to health problems. A choice of drinks should be made available day and night, such as fruit juice and water. In the later stages of dementia, it may be helpful to assist eating and drinking by bringing the cutlery/cup to the person's mouth.
- People with dementia have difficulties describing pain, a sore mouth or sore tummy might have an impact on appetite.
- The person's carer should sit with them during mealtimes. Sometimes describing the food, what it tastes and looks like may help the person.
- People with dementia often have a preference for sweet food. Combine sweet with healthier options, for example honey on wholemeal bread. And keep the dessert out of sight until the main meal has been finished. Only give one course at a time.
- Use napkins rather than bibs.
- Small regular meals might be more suitable than 3 large meals.



Using open shelves, removing cupboard doors or putting photographs on the outside to show what they contain can help in the kitchen.



Sleeping

Potential issues

- Night time waking and walking around the house
- Refusing to go to bed

Ideas to try

- Put a photograph of the person on their bedroom door. Not a recent photograph, but from when they were younger. A recent photograph, even of themselves, may not be recognised if their long term memory is working better than short term.
- Rearrange the furniture in the bedroom to make a clear walking area.
- Use a different coloured bottom sheet to the top sheet, or duvet cover. Avoid patterned bed sheets/duvet cover, instead use plain bed sheets.
- Use a mattress and pillows on the floor. The person may not want to climb into a bed if it is no longer familiar, but may recognise and use the bedding on the floor. This will also soften a fall if the person has difficulty getting in or out of bed.
- Remove or cover mirrors in the bedroom as this can create an impression of an intruder. When a person has dementia they may not recognise themselves in a mirror and can become distressed at their reflection.
- Use soft lighting to guide the person to the toilet at night, plus lights in the hall and toilet. Sensor lights, that come on automatically when someone gets up, may be used at night but can be alarming for some.
- Restrict the volume of the television in the bedroom and living area. This may minimise the impact on other household members and reduce potential agitation caused by too much noise.
- Carers wearing night time clothing at night can help the person understand that it is night time.
- If a person wakes up in the night, check that they are not in pain, or needing to go to the toilet.
- If the person cannot go back to sleep, consider doing a quiet one-to-one activity with them, and when they are calm take them back to their bedroom.
- A main exit can be painted the same colour as walls on the inside to deter someone from leaving alone.



Mirrored doors on the wall or dressing table can cause confusion in a bedroom. A mirror at the end of a bed can have the same effect.

Walking and the outdoors

Potential issues

- Pacing up and down repeatedly
- Leaving the home and walking with no apparent purpose

Ideas to try

- Pacing and walking will be for a reason. It is often due to the person looking for something or someone, such as a family member, even if this person is deceased.
- Open plan living is preferred due to clearer visibility, although pictorial signs will show what is behind a door, such as on bathroom, cupboard and bedroom doors.
- Reduce the number of doors if possible. Ideally doors to the bathroom and bedroom will open outwards or concertina style to allow access if the person falls.
- Pay attention to doors according to their importance for the person and highlight them using primary colours in a contrasting colour to the wall. Bright colours are more easily identified, pastel colours can be seen as grey.
- The main exit from the house may be disguised as a window with a curtain, as a visible door is an invitation to go through it. People with dementia have a reduced capacity to judge risks or danger.
- A safe enclosed path in the garden can provide exercise, activity and a distraction. Additional seating should be provided for rests. The pathway may be personalised to take account of the person's previous interests, such as incorporating raised flowerbeds.
- Give the opportunity to go for a walk with a carer to a shop or park. This way there becomes a purpose, such as buying a newspaper or feeding the ducks. There may be a desire to go somewhere that the person with Down's syndrome regularly attended in the past, such as a day centre or church, although they may not be able to vocalise this.
- Avoid plants that have poisonous berries as these may be eaten.



A white door may become lost against white walls. This may be useful if you do not want the person to use this particular door.



By painting the door and/or walls in different colours access becomes much clearer and easier to identify. Try to create a safe walking path outside if possible.



Try to create a safe walking path outside if possible.

Pain

Potential issues

- Unable to communicate or recognise that they are in pain
- Changes in behaviour with no known reason
- Saying they are in pain, but unable to show where the pain is coming from.
- Loss of appetite, distress, increase levels of self-harm or targeting one area of the body

“ If there are changes in behaviour, firstly check for a urinary tract infection”
- May

Ideas to try

To prevent pain:

- Ensure the person has an annual check up by the GP, and during this appointment has their thyroid level checked.
- Make sure they visit the dentist regularly. Maintain good oral hygiene and regularly check their mouth for ulcers.
- Help and support the person to eat a healthy diet and keep hydrated.
- Encourage and support the person to take regular exercise, or do some light physical activity.

To help support a person who is in pain:

- People with Down's syndrome do not have a higher pain threshold. They find it difficult to recognise the feeling as pain and locate the pain.
- When booking a doctors appointment, ask for a longer appointment, this gives carers and the person more time to explain what is wrong and ask any questions.
- Follow the instructions on medication exactly. Medication is only effective if taken regularly and at the right dosage level.
- Try to find activities that will distract the person from their pain but not make it worse, such as listening to music, a walk, life-story work, going outside and looking at the wildlife.
- Do not expect the person to ask for pain relief, instead provide pain relief when you feel they are in pain.

Things to do together

Ideas to try

- Introduce activities that are individualised and enjoyable to the person with Down's syndrome.
- Play music 15-20 minutes at a time, ensuring the music is recognised and liked by the person with Down's syndrome. Choose music that the person enjoyed in their teens and early adulthood. If the person is agitated, play calming music.
- Create a memory box or a book about the person's life; where they are from, their family, what they like/dislike. Put into the book/box old photographs. Ensure that the experiences you talk about in the life story were all positive for the individual. It is best not to bring up negative experiences, but for carers to be aware of them.
- Life story work should be ongoing, and done with the person. When there is a quiet moment, bring it out and look at it with the person, do this on a regular basis. This book may also be useful if the person goes into hospital, to let staff know more about the person.

“ Karen still enjoys singing and dancing, it brings her back to reality”
- May, Karen's sister



Key points

Ideas to try

- Keep the environment calm, predictable, obvious, familiar, safe and failure free.
- Any changes to the living environment need to suit the person with Down's syndrome with minimal disruption to others living in the same setting.
- The psychological environment is important, not just the physical environment. A person with Down's syndrome may not be able to read the emotion on your face or detect your frustration or concern.
- The environment should not be adapted in isolation. Equally important is support for carers to ensure an understanding of the changes that are taking place in the person they care for.
- Too many changes too quickly can lead to an increase in confusion of the person with Down's syndrome, often mistaken for a progression in dementia.
- There is always a reason for a person behaving in a certain way. It is not deliberately to annoy or upset you. The hard part is finding out the reason and the trigger, plus accepting that before too long this may change and another issue will appear.
- Keep trying and retrying ideas and strategies. What doesn't work the first time may work the next time you try it.

This book is designed to help you care and support a person with Down's syndrome who has dementia.

Down's Syndrome Scotland provides support to families, carers and professionals who care for people with Down's syndrome.

If you would like to access further support please call us on 0131 442 8840.

For further information visit: www.dsscotland.org.uk



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