

Living with DEMENTIA



Adapting the home of a person who has Down's syndrome and dementia – a guide for carers

Down's Syndrome

SCOTLAND helping people realise their potential

Introduction

People with dementia will be affected by changes in behaviour at different stages of their illness. This book is a collection of potential issues that you may come across in the home, with suggested solutions. The possible reasons for these changes are explained to give an insight into how dementia is experienced by people with Down's syndrome.

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.

This book is designed to help you to care at home for a person with Down's syndrome who has dementia. Small changes in a person's home environment can make a significant impact on how they cope with dementia.

Confusing surroundings

Potential issue

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

Ideas to try

If this is a bedroom, put the person's photograph on their 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.

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 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.



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

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.

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.



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.

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.



**White food on a white plate may be difficult to see.
A coloured plate can make a big difference.**

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 is an interest of 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.



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

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.

Specific drawers or a separate reminiscence box can contain safe, familiar items for rummaging through either alone or with a carer.

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.



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.

Replace shower doors or cubicle with a curtain. This will allow for easier access and for help should it be needed.

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.

Colour the water in the toilet bowl to help men with their aim. Using food colouring again in the bath to identify the water and give an idea of how deep it is.

The type of flush used on the toilet and taps on the sink or bath may mean 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.



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.

Walking

Potential issues

Pacing up and down repeatedly

Leaving the home and walking with no apparent purpose

Ideas to try

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.

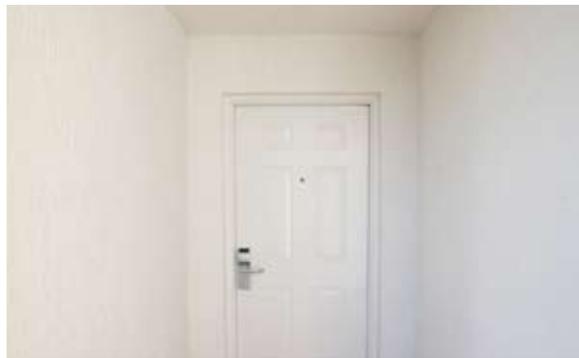
Pacing and walking will be for a reason. It is often due to the person looking for something or someone, such as a family member, even if this person is deceased.

Hang framed pictures on the wall next to an exit at the eye level of the person with Down's syndrome. The picture or photograph needs to have been meaningful to the person in their past rather than a current picture. If photographs of people are used, they should be labelled with names and the nature of their relationship to the person with Down's syndrome. Photographs of places or scenes should also be labelled to show where they are and when the picture was taken. This will enable carers and visitors to talk about them in the future.

Another option is to make use of different textures in a picture at eye level so this this can be touched.

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.

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.



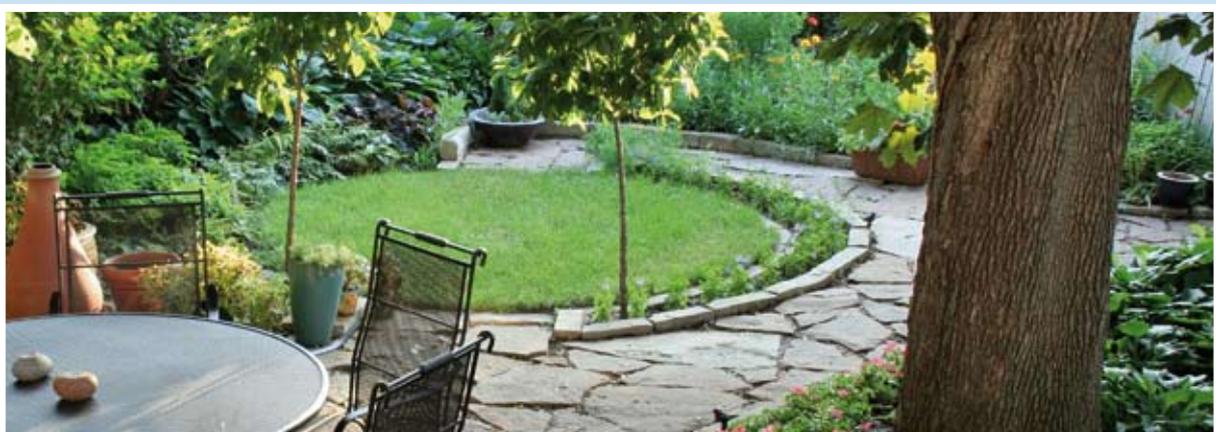
A white door may become lost against white walls. This may be useful if you do not want the person to use this particular door. By painting the door and/or walls in different colours access becomes much clearer and easier to identify.

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.

Avoid plants that have poisonous berries as these may be eaten.



Try to create a safe walking path outside if possible.

At night

Potential issues

Night time waking and walking around the house

Refusing to go to bed

Ideas to try

Use a different coloured bottom sheet to the top sheet or quilt cover. Different colours on the bed will help the person to know how to get in.

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.

Rearrange the furniture to make a clear walking area either around the room or from the bed to the door.

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.

A main exit can be painted the same colour as walls on the inside to deter someone from leaving alone.

Try to give an element of independence to allow control over activities and actions for as long as possible.



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.

Conclusion

- 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.



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