Cognitive Impairment and Dementia: A Practical Guide to Daily Living for Family Caregivers



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and the

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Introduction:

This booklet has been written to provide practical information to family caregivers of people living at home with a cognitive impairment or a dementia and to help them better cope with the day-to-day choices and dilemmas they may confront.

When you are caring for a person diagnosed with dementia or a cognitive impairment, sometimes the home and negotiating its surroundings can pose difficulties and can be dangerous. Yet without much effort, your home and its surroundings can be adapted to make it safer for everyone.

Detailed in this booklet are simple suggestions about changes/adaptations that can be made which may make daily life at home safer and more simple for you and your relative.

Remember not all of these suggestions will apply to you, nor are they foolproof. They are merely tips and do not and will not work for everyone. They may however help some people overcome the early practical difficulties that living with a cognitive impairment or dementia creates. Remember too that if any of these issues become extremely problematic, Health Service Professionals are available who have the specialist skills needed to assist and advise you in more depth.

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Promoting Safety and Security at Home:

Simple and subtle changes may make the home environment safer for everyone.



- Try to reduce clutter around the rooms in the house, in the hallway and on the landing upstairs.
- It may be necessary to remove certain objects if causing problems, such as matches, lighters, detergents, irons, medicines, alcohol, knives, scissors, gardening equipment and any other items which may pose a hazard.
- Make sure no electrical wires are loose or poorly attached.
- Make sure furniture particularly chairs are sturdy and not blocking access to other rooms and areas.
- Remove unnecessary furniture, or replace old pieces with more practical furniture.
- Change or remove rugs if they are likely to cause your relative to trip.
- Do not wax the floor.
- Make sure steps and stairs are clearly marked and non-slip.
- If your relative is prone to falls, consider installing an extra stair rail.
- Avoid sharp differences in the colour of the floors, especially dark colours people
 with a cognitive impairment or dementia sometimes view dark patches or particular
 designs on the floor as obstacles and may try to jump over them.

Promoting Safety and Security at Home:

Due to perceptual problems, people with a cognitive impairment or a dementia can sometimes get lost inside their own homes and may have difficulty distinguishing one room from another. They may also have difficulty differentiating appliances and equipment within rooms. Some simple approaches can be introduced which may prevent people feeling lost or confused inside their own homes.

• Inside the house, place clear and visible written signs or pictures at eye level at the entrance to each room, to remind the person what room he/she is in, or what should be done in this room - for example:

A picture of a toilet outside the bathroom/toilet,

or keys beside the front door.



- Keep the home environment consistent and predictable and in particular try to ensure that furniture stays in the same place the fewer changes made the better.
- To reinforce self-identity, place large pictures of family members and friends around the house, complete with nametags.
- Attach a sticker (where possible) to appliances such as the toaster or coffee maker describing what the appliance does and put notices on doors and cupboards as a reminder of what is inside the cupboards/behind doors.
- Clear and simple instructions on how different kitchen appliances work may help people with an early stage cognitive impairment, for example how to put the coffee maker or kettle on. This is only useful as long as the person can understand instructions.

Lighting in the home:

- Make sure the whole house is adequately lit and avoid floor or table lamps that can easily fall over and cause accidents.
- Reduce glare or reflections from windows that can cause further confusion or may be misunderstood.
- If mirrors create confusion or cause adverse reactions, cover them over or remove them completely.



Keeping track of time:

- Have a large clock with big figures easy to see in a prominent position in the kitchen or breakfast room or in a room most often occupied.
- Have a large calendar visible in the same room. It may be helpful to cross out previous days so today's date is more obvious.
- You can also purchase clocks which show the date and day.
- A day or weekly planner filled out in advance can help structure the day. The planner can be used as a reminder of what day it is and what should be done on that particular day.
- A visitors book can jog one's memory about who has been visiting the house and when visits were made.



Promoting Safety in the Kitchen:

Regardless of whether a person with a cognitive impairment or dementia can cook independently or not, the kitchen including its appliances and equipment, can sometimes pose safety problems. Here are a few simple tips that may assist in overcoming some of these problems:



- Keep a regular check on the fridge to ensure foods
 (particularly meat, cheese and eggs) and drinks (particularly milk/cream) are not out of date or decaying.
- It may be helpful to use different colours on the kitchen table, for example white plates against a red tablecloth.
- Be conscious of the fact that a person with a significant cognitive impairment may not be able to distinguish hot from cold and can therefore get burnt on food or drinks.
- When needed, install timers to control electrical outlets or stove, coffee maker and other appliances.
- Remove all sharp objects, chemicals/detergents, dishwashing liquids/tablets if they cause a problem.
- If possible, control the water temperature in the boiler to avoid the risk of scalding or burning.
- If needed, install tamperproof locks on stove/oven.
- If fiddling with gadgets becomes a problem, arrange to have stove knobs and oven door handles removed or alternatively use gas or electrical isolator switches that are concealed or awkward to access.
- Smoke alarms and gas detectors are also useful.
- Ensure your relative can boil water safely. A kettle is usually the best option.
- Swallowing may be problematic for a person with a more advanced cognitive impairment. Where this is a problem, try to remain present when a person is eating. It may also be useful to cut food into small pieces or if necessary and particularly in the case of advanced cognitive impairment, it may be advisable to prepare food in liquid form. You may also find it helpful to make an appointment to meet with a Dietician or Speech and Language Therapist. These Health Service Professionals are specially skilled in assisting you deal with dietary and swallowing difficulties.

The Bedroom:

People with a cognitive impairment or dementia may experience a change in their sleeping patterns. Their Circadian Rhythms may be impaired and they may mix up day and night and wish to get up during the night, thinking it is daytime. Bedrooms should as far as possible remind people that they are peaceful places for rest and sleep. They can be nicely adapted to foster comfort, relaxation and calmness.



- A balance of colour in the bedroom is useful to ensure it remains interesting yet does not prevent sensory deprivation. Avoid using garish colours such as reds or purples which may over-stimulate.
- A mix of contrasting colours in the decoration of the bedroom creates visual enjoyment,
 as well as reinforcing the identity of a particular room.
- Ensure lights are bright enough to illuminate the room clearly; however avoid lights that produce glare or shadows.
- Night-lights may be helpful for a person prone to getting up at night and can be used to illuminate clear pathways to the bathroom making it safer and faster to access.
- A bed occupancy sensor can alert you to when the person has left bed and the length of time he/she has gone (See links on backpage for stockists).
- Try to ensure the temperature in the bedroom is suitable for persons with a cognitive impairment who may be unable to communicate their feeling too hot or too cold. People with a cognitive impairment are sensitive to temperature changes and drafts.
- Keep a large clock and a calendar visible in the bedroom so the person always knows what day/time it is.
- In the bedroom avoid loose mats or inappropriately placed furniture which may cause accidents

Appropriate Clothing and Dressing:

- If dressing becomes problematic, try to use clothes that do not restrict mobility and are easy to put on. For example, stretchy, elasticated clothing without buttons or fastenings, may be helpful.
- If tying shoelaces is difficult, it may be helpful to consider buying slip-on or velcro fastening shoes.
- Use indoor-shoes or socks with rubber soles to avoid slipping.
- Shoes that have a low/no heel are useful if your relative is unsteady on his or her feet.
- Leave clothes out in the correct order for dressing.
- If you have any doubts please consult an Occupational Therapist.



The Bathroom:

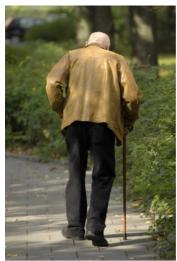
The bathroom is an essential room at home for all of us. When a person acquires a cognitive impairment, the bathroom can sometimes be avoided as it may be frightening and may pose serious threats. You may need to consult an Occupational Therapist for more specialist information and advice about bathroom adaptation but in the meantime, here are a few simple suggestions that may be useful and may encourage people to use the bathroom more often:

- Try to make the bathroom warmer and more comfortable by turning up the heating in winter time or by placing a battery operated radio or tape recorder on a shelf with favourite music playing.
- If your relative is unsteady on his or her feet, a properly installed shower chair in the shower (provided the area is sufficiently large) reduces risks of falls.
- It may be helpful to remove stoppers from the sink and bath to avoid flooding.
- Remove all electrical appliances that could be dangerous if dropped in water.
- Remove all medications from the bathroom cabinet.
- To avoid scalding, mark hot/cold water taps with large letters.
- Magiplugs can be used to prevent overfilling of the bath. (see back page for stockists)
- Properly designed grab rails can be installed near the toilet and bath/shower to assist getting on/off the toilet and getting in/out of the bath or shower.
- If possible, add a shelving unit behind the toilet to display toilet paper, towels and other useful items.
- It may be advisable for security purposes to remove the bathroom lock or have one that is easy to open from the outside on the bathroom door.
- If changes are being made to the bathroom, remember to try to keep the original taps and the toilet–flush handle, since they will already be familiar to your relative.



Getting Lost Outside the House:

A person with a more severe cognitive impairment, is liable to get lost outside the house even in familiar places. This can be embarrassing, frightening and potentially dangerous for the person and can also be very worrying for family members. A few simple tips may help prevent people with a cognitive impairment from getting lost. These suggestions may also make the process of finding the lost person a lot easier.



- Make sure your relative always carries some form of identification. For example, keep a
 discreet note in his or her pocket with name, address and phone number or the name
 and phone number of a carer to contact. If the person wears glasses, a label with
 name and address inside the glasses case may be useful.
- Identity bracelets similar to those worn by people with diabetes which include name and phone number can be useful.
- It may be advisable to notify your local Garda station about the possibility of your relative getting lost, so that the Gardai will already know the situation and will know what to do in the event of the person getting lost.
- Whenever possible make sure the neighbours are aware of the situation so that they can be on the lookout if anything untoward happens.
- To ensure that the home is accessible to others, remove the security chain from the inside of the front door.
- Leave a house key with a close friend or neighbour or identify an external key safe that
 is both safe and accessible.
- If in doubt, please consult your GP.

The Garden:

Gardens have the potential to be a great source of enjoyment for all of us. They can be creatively adapted, made safer and particularly peaceful for those with a cognitive impairment or dementia.



Gardens can be used as a therapeutic tool, to ensure

that we can relax in the fresh air and have all of our senses stimulated. By spending time outdoors in a carefully designed garden, we can be exposed to different fragrances, experience different textures, see diverse colours, listen to natures' sometimes soothing sounds, experience sunshine and when possible sample the garden's berries or fruit. A few changes to the garden can make it a haven for a person with a cognitive impairment or dementia.

- Try to use plants and shrubs that provide colour, texture and are of seasonal interest.
- Choose popular garden plants which may prompt memories. Avoid planting poisonous plants.
- Try to use plants that encourage wildlife such as birds and butterflies these may also trigger memories and provide visual stimulus.
- A moderate level of fragrance is a potent stimulant both for memory and for way marking – however too many strongly scented plants could be overpowering and could cause confusion.
- Light foliaged trees can be useful to create light shade; deep shadows can be confusing as dark patches can be perceived as objects instead of shadows.
- All seating areas should be sheltered from sun and wind, and should ideally have a
 central focus, enabling the person to look out at something interesting, for example a
 bird table or a small water feature.
- In your garden, try to provide a degree of privacy, but also ensure that no area is completely hidden from view.
- If the garden area is large, low fencing can be used to create small "rooms" within the garden.
- Ensure that there are sufficient resting and seating areas in the garden, and that there is enough space for large items such as wheelbarrows, prams or wheelchairs to get by.
- Large and stable pots can be used to create seasonal mini-gardens with suitable colours and scent.

Pathways, Pavings and Fencing in Gardens:

 The garden path should as far as possible always return to the house. Accordingly if designing a path within the garden, avoid abrupt changes and dead ends.



- In very large gardens, design the path to run through different sections of the garden to give a variety of visual experience.
- Allow the path to run through the lawn, enabling the person experience its texture.
- If the path has a steep gradient, make sure to provide handrails.
- Avoid trees with heavy leaves or that produce a heavy berry crop. These can be hazardous, as the leaves or berries may fall and form a slippery surface, or they can create a confusing pattern on the paving.
- If using paving, chose materials that are warm and domestic in colour and scale.
- Use non-slip and non-reflective material without cracks/divisions for paving.
- Fences or walls need only reach a height of approximately 5.2 feet. Avoid creating prisons.
- Design the fence to discourage climbing keep horizontal rails facing the outside and the finished part facing into the garden.
- Try to design the gates to merge with the fence, so that gates are not very visible or obvious.

Smoking:

- Develop a routine for your relative's smoking such as after a meal.
 This can allow the person to continue the habit without feeling supervised. Lighters and matches can then be put in a locked cabinet until the next smoking break.
- If locking lighters away is not possible, disposable lighters are now available which are safer and more difficult to operate.
- Keep smoking area clear of flammable materials such as newspapers.
- Install smoke detector/alarms in the home. Fire extinguishers/blankets are useful for emergencies. Ensure you know how to use them effectively and safely.
- Avoid loose fitting sleeves or cuffs that could catch fire. Smoking aprons are flame retardant and fit over clothes to reduce risk of setting clothing on fire.
- Ensure furniture is fire retardant.
- 'No Smoking' signs can act as a deterrent if placed in areas you do not wish the person to smoke ie the bedroom.
- Due to the risk of fire, you may need to consider always supervising smoking.
- The best option is to stop smoking. For advice and information about quitting smoking, contact the National Smokers' Quitline at Callsave 1850 201 203 or talk to your GP.
- An alternative to stopping smoking is using false cigarettes. This enables people believe
 they are still smoking thereby maintaining the habit.

Alcohol:

Remember people with a cognitive impairment or dementia may forget they have had a drink or that they have already consumed a number of alcoholic drinks.

 Discuss alcohol intake with the GP. The latter can advise on issues such as alcohol consumption and medication and other important matters relating to alcohol consumption.



• It may also be helpful to reduce the amount of alcohol available in the house by removing or hiding bottles or leaving only very small quantities available.



Use of Medicines:

Daily intake of medication may sometimes be critical to maintaining health and well-being. However it is not always easy to remember to take medication, particularly at pre-determined times and as a cognitive impairment progresses, taking tablets on a regular basis may become more problematic. Remember too that having a large quantity of medication lying around the house can often be



dangerous. You should return any discontinued medication to the Pharmacist. Here are a few other simple tips to avoid problems with medication:

- Use a medicine dispenser (these are medication reminder cases) to facilitate taking the correct amount of medication at the right time. If your relative has no medicine dispenser ask the GP for one or enquire at your local Pharmacy.
- Keep the medicine dispenser in a visible place e.g. beside the kettle, as a reminder of when to take the medication.
- An alternative to a medicine dispenser is a blisterpack. These are available in most local pharmacies the pharmacist prepacks the medications into blister packs and you or your relative can push out the tablets for each day.
- Enter the times that the medicines are to be taken in a daily planner, to make it easier to remember.
- Be alert to any side effects of medication, write them down if necessary and discuss them with your relative and doctor.
- Some medication for example can be prescribed in patch format or as a liquid. If your relative has difficulty taking medicine ask the GP can it be provided in another format.
- Except for the daily dosage, always keep all medication locked up.
- If in doubt, please consult your GP.

Driving:

Many people with a mild cognitive impairment continue to hold a Driver's License and continue to drive safely in familiar areas. However, eventually a person with a significant cognitive impairment or a dementia will, for safety reasons, have to cease driving completely.



Remember your relative is obliged to inform his or her insurance company if diagnosed with dementia. If the insurance company's doctor assesses your relative as still competent to drive the insurance premium will not be affected.

If you or your relative feel you have been unfairly treated, you can contact the Financial Ombudsman (01-662 0899) or the Insurance Information Service (01-676 1914)

The following are some early warning signs for family caregivers about the need to review a cognitively impaired person's driving competencies and consider the need for stopping driving.

- Becoming lost on familiar streets
- Difficulty in driving appropriately and remaining within one lane
- Mistaking or confusing levers on the dashboard, for example mistaking the indicators for the windscreen wipers
- Anger, irritability or poor judgement when driving
- Unexpected confusion at junctions, roundabouts or traffic lights
- Driving too slowly or too quickly
- Accidents, scrapes, or near misses
- Incorrect usage of signals
- Requesting guidance to drive from a passenger

Driving:

You should talk to your GP if you have any serious concerns about your relative's driving and seek advice about what action should be taken.

If you have niggling/minor concerns about your relatives continued driving:

Introduce if appropriate a gradual withdrawal from driving such as giving up night driving;
 rush hour traffic, driving in bad weather, not driving alone, only driving in local areas. Try
 to reduce the need to drive, and seek out alternative arrangements

If you have serious concerns about your relatives continued driving:

Explain to your relative that driving incompetently on the road may lead to a serious
accident and may place other motorists and pedestrians' lives at risk. Then insist on
getting an 'on-road' driving assessment – an assessor accompanies the person on a
drive and assesses one's ability to drive safely and competent.

If your relative is refusing to listen to your concerns, ask your GP or other doctor for advice.

Money Matters:

Using money including cash, cheque books and credit cards and managing one's finances competently can become a very challenging issue for a person with a cognitive impairment or



dementia. As the illness progresses, the individual can struggle with simple arithmetic and with identifying numbers. He/she may have difficulty with grocery shopping payments and with handling bills and accounts. The earlier the person gets a diagnosis, the easier it will be to broach the subject and come to arrangements that protect the person's finances while maintaining dignity.

The following should be seen as warning signs of the need to review your relative's independent use of money

- Repeatedly forgetting to pay bills.
- Paying bills twice.
- Mishandling finances in general.
- Becoming overly generous with money when paying for items in shops.
- Difficulty managing change for example letting Sales Assistants pick out the appropriate money from a wallet or purse.

If you have concerns about your relatives continued use of money

- Convert individual accounts to joint accounts to oversee transactions.
- Arrange with your bank/financial institution, and your relative, how they will access their finances.
- Have your relative carry only very small amounts of cash.
- Remember that by law, if one account holder can no longer manage the account, the bank is obliged to freeze the account until a Power of Attorney is activated.
- Other measures to protect finances include setting up direct debits for bills and a maximum withdrawal limit on the account.

Summary:

The material contained in this booklet draws on a wide range of information gathered over time from the dementia care literature, from formal and informal caregivers and from other available resources. We hope this information will provide you with some practical advice on the day-to-day management of some of those distressing dementia-related problems you may encounter. Many people with a cognitive impairment or dementia will continue to live safely at home and this booklet attempts to describe how their home environment can be easily adapted to compensate for the disability of dementia and to promote dignity and more independent living. Remember, no two people with dementia or a cognitive impairment will be alike, nor will the suggestions forwarded in this booklet work in all cases. The onus is therefore on you as a family caregiver to be flexible and resourceful and to pick and choose from this resource booklet pending your needs and pending the course and stage of the illness your relative experiences. Finally we hope this booklet will be of some assistance to you in your caregiving journey.

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Useful Contacts:

- Living with Dementia, Trinity College Dublin. Phone: 01 8962914, email: forsytc@tcd.ie or see website: http://www.socialwork-socialpolicy.tcd.ie/livingwithdementia/
- **DSIDC,** St James's Hospital. Phone: **01 4162035,** email: dsidc@stjames.ie or see website: www.dementia.ie
- The Alzheimer Society Of Ireland. National Helpline: 1800 341 341, email: info@alzheimer.ie or see website: www.alzheimer.ie
 Health Service Executive: http://www.hse.ie/eng/ Call Save 185024 1850
- Senior Helpline: LoCall 1850440 444
- Occupational Therapists' Association: Phone: **01 6337222**, email: aoti@eircom.net or info@aoti or see website: http://www.aoti.ie/
- Speech and Language Therapists' Association. Phone: (0)85 7068707, email: info@iaslt.ie or see website: http://www.iaslt.ie/

Aids Stockists:

- Emergency Response. Magiplug, Bed/chair occupancy sensors and other useful aids: Phone: 1850 247 999 or 053 937 6949, email: sales@emergencyresponse.ie or see website: http://www.emergencyresponse.ie/
- **Telecare.** Phone: **1800882247**, email: <u>foldtelecare@foldireland.ie</u> or see website: http://www.foldireland.ie/telecare.php
- At Dementia. Phone: +0044 116 257 5017, email: info@trentdsdc.org.uk or see website: :http://www.atdementia.org.uk/productSearch.asp?page_id=16
- Assist Ireland. Phone: LoCall1890 277 478, email: support@assistireland.ie or see website: http://www.assistireland.ie/eng/

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