



Assisting People with Advanced Dementia with their Personal Care: Ideas and Tips for Carers



A booklet created from the Pro-CARE study

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About this booklet

This booklet was developed as part of a research fellowship funded by the Alzheimer's Society and conducted at the University of East Anglia. The research was led by Dr Tamara Backhouse with support from Prof. Eneida Mioshi and Dr Anne Killett. The research was undertaken with family carers and care-home staff who were physically assisting a person living with advanced dementia with their personal care. The tips and ideas included in the booklet stem from interview, observation, and questionnaire research.

We would like to thank our person living with dementia and caregiver participants for taking part in the study, our family carer and care-home staff advisors who assisted us with the development of this booklet (Peter Davis, Julie Lang, Clare Carey, Derek Buttle, and Emily Allison) and our workshop attendees who provided suggestions for improvement.

The tips and ideas presented are not guidance or instructions. They are a collection of actions and approaches which other caregivers have found useful. You may, or may not, think the ideas are worth trying in your situation. **Everyone's dementia journey is different – not all situations arise for all people.** The ideas are not expected to work with every person, in all situations or at all times. The booklet was developed to be used as a reference book to dip into and choose anything that you think may be of use to you at different points during your caring journey. The booklet is for those caring for people in the moderate-to-advanced stages of dementia.

*This booklet is for both **family carers and care home staff**. Although most ideas are applicable for both settings, there may be some ideas, which are not suitable for your situation.





"Caring for someone is brave, essential, and key for life and love: The thing to do!"

(Quote from a research advisor)

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Overriding Principles for Care

Several general principles or good 'rules of thumb' for care were identified and this section has been created at the beginning of the booklet to prevent the need to repeat them all the way through. Safe to say they have relevance for almost every section of the booklet!

- If possible, promote independence and try to involve the person.
- Observe, prompt and gently remind the person.
- Monitor the person when conducting their own personal care.
 - o If the person is struggling, offer to help.
 - You may need to help the person more when they are tired.
- Position yourself so you are comfortable to carry out the care activity and not intimidating to the person.
- Communication is key. Connect with the person, move physically down to the person's level, speak to the person clearly, build trust and encourage. Explain what you are doing / talk the person through the care activity.
- Make sure you have time for the care activity or try to complete the care
 activity at a different time to suit you and the person you are supporting.
- **Provide reassurance** to the person throughout, let them know they are okay and doing the right thing.
- Demonstrating the activity may be useful.
 - Try to address any unmet needs such as, pain, hunger or thirst.
 - Is the person well?
 - Can you adapt your approach?
 - Think about timing, could you try at a different time of day?
 - Acknowledge approaches or strategies may not work all of time. What is difficult now may not be in a month's time.
 - You may not be able to complete all care activities if the person is not keen.
 - Seek support.

Is the care activity essential? If not, could the person have a dressing gown day or another mode of care such as dry shampoo rather than a hair wash?

If care is difficult

Nail Care

- If possible, **promote independence** and encourage person to trim their nails themselves if they can. For example, are they able to file their nails?
- Offer help if the person is struggling to cut their own nails.
- Wash and clean nails as part of hand washing.
- Soak nails in water to soften them before cutting.
- You could try cutting nails in water.

Be as gentle as you can

- Try to **position yourself well** in relation to the person's nails.
- Use your tool/s of choice (manicure tools, scissors, clippers, nail files).
- Consider a chiropodist for toenails, especially if the person has diabetes where risks are higher if skin is accidently cut. If the chiropodist is used regularly, they can get to know the person.
- You could use a metal file for fingernails. This can work well if carried out often, particularly if the person has diabetes. This can avoid cuts to the skin.
- Cut little bits at a time if nails are very long, cutting is difficult, or to finish off.
- Only cut nails as short as you think you can safely.
- If the person is unsettled, try to cut nails quickly.
- If it is not going well, leave the activity for another time.
- You may want to use a manicurist.
- Use nail cutting as a pamper or bonding session, or an activity to pass the time.
- You could use hand cream or nail varnish if acceptable to the person.

To make it easy to tidy up, you could lay something down like a towel to catch the nails or cut them when the person is outside



ail scissors by Abby from the Noun Project

Skin Care

- If possible, **promote independence** and encourage the person to carry out their own skin care.
- If the person still completes their own care, remind them to apply creams and check they apply the right cream for each area.
- Creams can be used to maintain skin suppleness, protect sore skin, or reduce dry skin. Creams can also prevent scratching, as can a scratch suit (clothing) to wear at night.
- Wash and dry skin thoroughly before applying cream. Find a suitable time/place for you to apply cream; this could be after washing in the morning or the evening.
- You could use a soap substitute to bath, shower or wash the person. These are gentler on the skin and moisturise while washing.
- Check skin is intact and not sore. Pressure areas such as the heels, balls of feet, sacrum/bottom, elbow, ears, or hips can get sore, and the skin can break down. Monitor these areas to see if they get red or sore.
 - O It is important to encourage the person to stand up and walk around or move regularly during the day not just to sit in one place, as this can stop skin on their bottom from breaking down. Particularly if the person has issues with continence and wears pads. Use creams to keep the skin in good condition. Barrier creams can protect skin from incontinence. Monitor any sore areas. Click for information about pressure sores and prevention.
- Speak to the person's General Practitioner about the type of cream needed. Use the correct creams for each area.
- If the person has a pressure ulcer, consult with professionals to find out the best way to treat it.

Don't forget to check if the person has dry lips



kin care by Pawinee E. from the Noun Project

Applying cream can be a pampering activity

Dressing / Undressing

- If possible, **promote independence** and encourage the person to dress or undress themselves.
- If possible, dress the person to their preferences and the clothes they have always liked.
- If dressing is difficult, you could buy simple clothes such as loose t-shirts, V-necks, tracksuit bottoms, stretchy clothes, or cardigans rather than jumpers. You could add elastic to the person's usual clothes. Try out different bra types if these prove difficult to put on.
- Perhaps start the activity off for the person such as doing up the top button. Get clothes out ready for the person. Put clothes in a familiar place, leave clothes the right way around and in the order that they will be put on. Check for and remove inappropriate or dirty clothes, and only provide clean clothes.
- Think which place may be best for dressing activities. Would this be the bathroom, bedroom or somewhere else? Is there enough space? Is there somewhere for the person to sit if needed?
- Try to not offer too much choice if this disrupts the person's focus.
- Time care activities carefully. When is the best time to assist someone to get ready for bed? It may be earlier than bedtime when the person still has some energy and is not too tired.
- Keep the person warm throughout. Perhaps warm your hands before helping the person. Use a dignity towel to cover the person (for example, on their lap), always try to keep something covering the person as this can build trust.
- A shoehorn may be useful.

Leave some shirt or blouse buttons done up, so there are less buttons to manage



Clothes by AB Designs from the Noun Project



If the person has
dressed
themselves, try to
overlook small
dressing
discrepancies if
addressing them
will upset the
person

Dressing / Undressing Continued...

- If the person has difficulties with understanding or moving, you could minimise the amount of transfers/standing up or sitting down they do. For example, you could take off and put on the all the bottom half clothes at once. Some people have found putting a skirt on over the person's head successful.
- If the person has one arm that is more flexible than the other, dress the least flexible arm first. You may find it easier to put your arm the wrong way through the armhole, hold the persons hand and thread the garment onto their arm. It may help to get the person to hold shirt sleeves when putting a jumper on over a shirt.
- If caring for the person on the bed, roll them to enable getting clothes
 on and off. It may be easier to dress the top half first when you are
 getting them dressed on the bed. You could put items like a cardigan on
 once the person is sitting up.
- Don't forget the important finishing touches such as beads, a broach, tissue or glasses.
- If dressing is difficult, consider the person having a dressing gown day.



You could provide something for the person to hold while you are dressing them to distract them

A hoist (lifting device) may be used to assist a person to move with comfort if they can no longer move themselves. If the person uses a hoist:

- When dressing, pull clothes up/down as much as possible before getting the sling in place and hoisting.
- If the person wears a skirt, you could put it on over their head.
- When undressing, bring bottoms down as much as possible before sitting / laying the person down.

Medications

- If possible, **promote independence** and encourage the person to take their medication themselves.
- Try to find out the person's thoughts/wishes about tablets/medications and consider them as much as possible. If possible, go along with the person's preference for taking medications.
- Prompt medications and remind the person to take them. You may have to explain what to do with the medications.
- You could use a dark tub, so the tablets are more visible to the person.
- Make sure soluble tablets are separated from any others and placed in water.
- If behaviours are very difficult, contact the person's General Practitioner or the local Mental Health Team or Crisis Team. They could provide advice, support, or review medications that may address difficult behaviours.
- If a urinary tract (water) infection is suspected (see page 24 for more information), see the person's General Practitioner. Try to get a urine sample before you go.
- Provide medications at the relevant time/s.







Watch to check that medications are taken. Look for any medications that are spat out or dropped

Find out from the prescriber:

- Whether medications are still needed. Ask for a professional medication review to see if medications can be reduced or stopped. Seek professional guidance, especially if changing medications.
- If any medications can be omitted now and again if the person is refusing.
- Whether certain medications need to, or can, be taken with or without food and/or drink.
- If medications are time critical, if not and the person is not keen on taking them, try to give them at a different time of day when the person may be more receptive.
- If liquid or chewable versions of the medications are available.

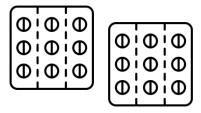
Medications Continued...

- To simplify organising the medications, you could use a dispensing system such as a Dossett box or blister pack. Ask your pharmacist about these.
- You may be able to have medications delivered, ask your pharmacy.
- Put medications in the person's hands if appropriate. It may help, with the person's permission, to put the medications in their mouth for them. A spoon could be used to do this.
- If the person has not taken their medications, try again if they are not too distressed.
- If eardrops are used, have a tissue ready and leave hearing aids out for a time.
- Don't forget creams are medications. You may want to wear gloves when applying them.
- Administer eye drops as part of your usual routine, so not forgotten.
- You could lock medications away if they may be accessed inappropriately. If the person has taken an [accidental] overdose get professional advice/help as soon as possible.
- If medications are being refused and options such as liquid medications have been tried, speak to the person's General Practitioner, they may have some ideas to help.
- Watch out for possible side effects of medication. Seek professional advice if these appear.



medication by Evan Bond from the Noun Project

Think about the order you administer the medications. Choose the best way for you. It may be best to start with the most important medication.



medication by Made from the Noun Project

Washing

- If possible, **promote independence** and encourage the person to wash themselves.
- You may have to prompt the person and supervise them throughout the activity. Talk to the person, explain and work together. The person may need more help when they are poorly, upset or confused.
- Try to get everything ready before starting.
- Choose a suitable place to wash, maybe by the sink or seated nearby.
- You may want to protect floor from the water.
- If the person is standing, make sure there is something for the person to hold on to so they can steady themselves while being washed.
- You may find it easiest to wash the person while they are sitting, a perch or other type of chair can be useful for this.
- You could put a towel on the chair if the person is seated while undressed.
- Seat the person to wash their feet; you could soak feet in a bowl.
- Washing the groin area may be easier while the person is laying on the bed.
- Minimise moves if necessary, for example wash and dry the top half and legs/feet before standing to do the bottom and groin area.
- Keep the person wrapped up and as warm as possible. Use towels to cover the person for their dignity. Try not to undress the person completely, wash one area at a time (for example, top then bottom of body).
- Wash where it seems appropriate first depending on the situation or how the person is on the day. From top to bottom is the ideal and from front to back in the groin and bottom area to reduce the chance of infections.
- Try to wipe any faeces away before washing.



Try not to forget to wash the person's hands

Washing Continued...

- Check skin for sore areas and monitor any existing sores.
- You could wash the person with exfoliating gloves.
- Wash creams off and dry skin before re-applying any.
- You could try changing the plug and/or taps on the sink, so they are easier to use and/or the person recognises what they are.
- If the person is used to using soap, they may recognise and prefer a bar of soap.
- Alternatively, liquid soap in the water may be easier than a bar of soap.
 Many people do not use soap on their face. You could use a washing cream and a special glove such as a Tena Glove to wash the person.
- Dry thoroughly and check skin, especially in creases such as under the person's breasts or folds under the stomach. These areas tend to become sore especially in hot weather; thorough washing and drying can prevent soreness. Barrier cream can be used if required.
- Often people have a smaller wash, or do not wash, when getting ready for bed. If the person refuses, just do what you can when you can. Prioritise the most urgent activity or area.



To prevent scalding:

- Install a maximum hot water temperature device.
- use a scold prevention hotspot an item that is placed in the water and changes colour to show the temperature.
- Check the water temperature with a thermometer or your elbow (a sensitive area) before using.

Shower / Bath

- If possible, promote independence and encourage the person to bath / shower themselves.
- Choose convenient time of day and allow plenty of time.
- Prompt next step to the person if needed.
- Before the shower or bath, get everything you may need out ready, make sure the room is warm.
- Obtain and use appropriate equipment such as a bath or shower chair or grab rails. An occupational therapist (OT) could assess your situation and help you access the correct equipment.
- Position yourself somewhere comfortable, so you do not hurt yourself.
- Explain what you are doing and talk the person through the process.
- Regulate the water temperature so it does not get too hot or too cold.
- Assist the person to keep safe when getting in and out; most care homes
 will have baths with easier access (for example, rise and fall chair). If it is
 unsafe or too difficult to get the person in or out of the bath or shower,
 offer a strip wash.
- For easy dispensing, you could use wall dispensers for shower gel or shampoo.
- Use a soap substitute to protect skin if needed.

Offer as much privacy as is possible

- If appropriate, discourage the person from bathing/showering when you are not around for safety reasons.
- If washing the person's hair, face or feet is difficult, leave them for another time when not in the shower or bath. Consider getting a shower cap. If not, wash hair, face and feet as part of the bath or shower.
- Prepare to keep the person warm after. For example, put the heater on or warm the towels. Wrap the person in towels after to keep warm.
 Consider putting clothes on the radiator to warm them. If appropriate, work quickly so the person stays warm.







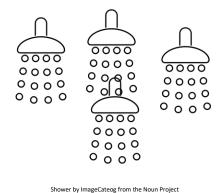
Shower by Arthur Shlain from the Noun Proje

Shower / Bath Continued...

- If a bath or shower is an issue, leave it for a day, or provide a strip wash or bed bath (see washing section).
- You could start showering legs first, so the person does not get cold if sitting.
- There is no need to bath/shower the person every day unless they prefer it or need it for clear hygiene reasons
- Being showered by someone else can create a lot of fear and anxiety. It can be helpful to start showering the person from the bottom (feet upwards) instead of the top (head downwards) to ease these feelings.
- To keep the person involved offer the person another towel to hold while you are drying them.
- Have somewhere to sit ready for person if likely to be needed. Put towel on a chair and the floor (if appropriate) for when the person gets out.
- The way you ask may be important (see communication section). Use encouragement or communication strategies to get person to understand and agree to a bath or shower. It may help to let idea of bath or shower sink in, alternatively some people worry less if they have little warning before an activity takes place.
- In care homes, match the sex of carer if possible and preferred by the person.
- Use the care activity as an opportunity to chat.
- Dry toes well. Use powder if appropriate.
- If the person self-cares, check for clues that person has had shower. You may want to supervise them for safety reasons.
- Following a routine may be helpful.







Hot shower by Creative Mania from the Noun Project

Shaving

- If possible, **promote independence** and encourage the person to shave themselves.
- Perhaps let the person start and then help them to finish.
- If needed, monitor and supervise the person if they shave themselves.
- Learn what you can from person about their preferences/how they shave.
- If you are nervous about shaving the person, just have a go. Be delicate and try to be precise. Shave slowly if the person grows very coarse hair.
- Shave the person in a place/position where it is comfortable for you.
- Make sure false teeth are in before shaving. Make sure the skin is taut before each stroke. You may have to gently pull it tight with your other hand.
- Talk to the person and explain what you are doing.
- It may help to shave the person before they are dressed.
- If the person is not keen on being shaved, try another day or time. Shave when they let you, this may not be every day. If shaving is difficult, and the person agrees, you could leave them unshaven for a day or so, or grow a beard, which may be easier to manage.
- Consider using a professional barber to shave the person.
- There may be hairs that the person can no longer pluck themselves, use scissors or tweezers to remove these.

 Try different options, would a
- Beards may need combing.
- Provide tweezers to ladies.
- Buy an electric shaver, these can be safer, especially if the person has diabetes or is on blood thinners to avoid any cuts. Replace shaver blades and clean the razor.
- Keep shaver/razor in a safe place so it does not get lost.





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razor be best, or an electric shaver

Shave by Vectorstall from the Noun Project

Shave by P Thanga Vignesh from the Noun Project

Oral Hygiene

- If possible, **promote independence** and encourage the person to clean their own teeth.
- You could get items ready, such as lay the brush out and take the top off the toothpaste or leave toothpaste on the brush ready, so you know whether the person's teeth have been cleaned.
- Some people find it helpful to only leave the person's toothbrush out and remove other brushes. You could put more than one toothbrush out for the person to choose from.

 Try an electric or manual toothbrush if the other is not acceptable to the person. You could try a Dr Barman's superbrush 3-sided toothbrush to make thorough teeth cleaning easier.

 Try change the timing or place of teeth cleaning. Is it more acceptable to the person before getting dressed or after? You could try different types or flavours of toothpaste

Does it help if you clean your teeth at the same time as the person?

- If the person is not at the sink, you could give them a brush with toothpaste, then have one empty cup and a cup with water in. After they brush, encourage them to spit into the empty cup, and if they want to rinse, to take a drink and then spit again after swilling. Placing a towel around their neck and on their lap can be useful.
- Do what you can, cleaning teeth once a day is okay if it is too difficult. There is no need to rinse toothpaste off.



Clean teeth by BomSymbols from the Noun Project



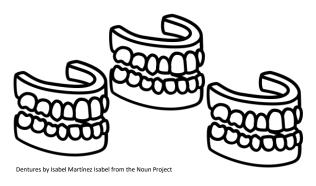
Brush Teeth by Phonlaphat Thongsriphong from the Noun Project



Teeth cleaning by Nook Fulloption from the Noun

Oral Hygiene Continued...

- Try to keep track of dentures and toothbrushes so they do not go missing, for example, check through tissues.
- Try to prevent the person from cleaning teeth for too long so they do not get sore.
- You may want to use gloves while helping the person clean their teeth.
- You could buy dental sticks if the person likes a toothpick.
- If the person is very poorly, you may need a mouth care kit to moisten and clean their mouth.
- Try to prevent chapped lips; dry lips thoroughly and consider using a lip balm.
- Has the person been seen by a dentist or hygienist recently? Consider getting an appointment. Some dentists do home visits.





Dentures:

- If possible, coax the person to take their dentures out. It may be easier to take the top ones out from the side.
- Try to get the person to rinse or brush their mouth after taking the dentures out to clean their gums.
- Clean then soak dentures if the person is happy to leave them out at night, if not clean them and put them straight back in the person's mouth. It does not matter if the person goes to bed with dentures in.
- Try not to put too much adhesive on dentures. You could use adhesive only on top teeth.
- As a last resort, you could clean dentures while in the person's mouth.
- Denture tablets could be mistaken for sweets so store securely.

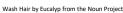
Hair Care Washing hair

- If possible, **promote independence** and encourage the person to wash their own hair.
- Try to wash hair when you have plenty of time a good time for you.
- Washing hair in the bath or shower: Remember to shield the person's eyes you could use a flannel or your hand. Smoothing hair with a damp flannel may be a good idea. Rinse off carefully. If appropriate, you could lean the person's head back when in bath or shower. Consider washing the person's hair last so they do not get cold. Consider switching the shower off while shampooing. You could unhook the showerhead for accuracy when rinsing.
- Washing hair separately to a bath or shower: Wash hair at a place that suits you you could consider the kitchen sink. Position yourself well so you can reach. Put a towel around the person's shoulders. Lean person forward over sink or bath. Obtain any equipment that may be useful such as an inflatable basin to use anywhere or a shower cone attachment. You could use a jug to rinse.
- Wash the scalp if the person is bald.
- Remove hearing aids before washing hair.

Baby shampoo is gentle to eyes

- Make sure water is not too hot, or pressure too strong, and try to rinse all shampoo out.
- Use dry shampoo if washes are infrequent or two-in-one shampoo to save steps during washing hair.
- Some Day Centres offer hair washing and bathing services. You could go
 to a hairdresser or consider a home hairdresser. If the same hairdresser
 comes in to do the person's hair, they can build a rapport with the
 person over time.









Shower by iconixar from the Noun Project

Hair Care Continued...

Managing hair

- If possible, **promote independence** and encourage the person to style their own hair.
- Consider a low maintenance hair style.
- Look at pictures to see how the person used to have their hair styled.
- Talk to the person about their previous hair styles and hair experiences.
- Brushing and stroking hair can be a good way to calm a person when they are upset, afraid or frustrated.



Hair Dryer by sachan from the Noun Project

If the person is not used to it, a blow dry can be distressing

Wig care:

- Care for the person's scalp or any hair under the wig.
- Keep the wig on in public for dignity.
- Make sure the wig is on the correct way and any hair is hidden under it.
- Style the wig when it is on the person's head.
- If acceptable, take the wig off at night.



Wig by iconixar from the Noun Project



Wig by Jacqueline Fernandes from the Noun Project

Eating / Drinking

- If possible, promote independence and encourage the person to eat and drink without assistance.
- Try to keep the person hydrated.
 - Offer a morning cup of tea (or other preference) and a drink before bed.
 - Tastes can change, so try new drinks.

Drink by Ranah Pixel Studio from the Noun Project

- Clear fluids in a glass may not be visible to the person, consider offering an appropriate coloured drink (for example, a sugar free drink if the person is diabetic).
- Use a clear mug so the person can see the drink.
- If alcohol needs to be restricted, you could make weaker/non-alcohol drinks for the person so they can join in when others drink.
- You could use a fluid chart to document drinking if you are concerned about the person's fluid intake. Advice on drinking is available here including daily recommended intake and a link to a fluid chart. You could try to encourage foods with a high-water content, for example jelly, fruit, ice lollies.
- Try to it in with the person's routine.
- Talk the person through what to do. If the person cannot manage to eat by them self, assist them with their meal.
 - o Find a comfortable position to assist with eating.
 - o Try to assist the person at their pace.
 - Gently touch the food to the person' mouth; this may prompt the person to open their mouth.
- You could involve other family members to help the person to eat or, if applicable, get paid carers in to help at mealtimes. Some family members assist when the person is eating if paid carers run out of time or cannot attend.

Encourage the person to eat







eat by Guilherme Furtado from the Noun Project

Eating / Drinking Continued...(1)

- If possible, assist the person to sit in a good position near a table. If not possible, let person eat where they like:
 - The person may prefer to sit with others while eating, be on their own or be anywhere they are comfortable such as their bedroom.
 - Some people may prefer to walk around while eating finger foods may be best.
- You may need to get specialist equipment such as a tiltable (Doidy-type) cup or cup with a lid and spout, high-sided plate or use a straw. You could try different spoons to see if the person can manage better.





Protect the person's clothes

Drink by Jens Tärning from the Noun Project

Plate by Left Martinez from the Noun Project

- Try to ignore messy eating if the person is eating independently.
- Take familiar items out with you if eating out. These could be spoons, napkins, a bib or apron, cup, serviette, dental sticks, particular colour or types of plates or cups (for example red) or something to protect clothes from spillages.
- Try to provide a healthy diet. A healthy diet can assist in managing diabetes and weight gain or loss. Try to see a dietician or speech and language therapist (SALT) if you are concerned about the person's diet or swallowing.
- You could order a child meal when out if the person does not eat much and will not be offended.



For care homes: a <u>DrinKit</u> toolkit is available.

For care homes and family carers: <u>The Hydrate Toolkit</u> is available.

Click the links to find out more.

Eating / Drinking Continued...(2)

• Safety – Ask yourself, can person manage regular food today? You could cut food up for the person. If there are chewing difficulties check the person has their dentures in and adapt usual foods to make them softer. Make sure the person sitting up. If the person has swallowing difficulties, you could puree food, offer wetter foods and assist to eat slowly. It may help to contact the person's General Practitioner for advice, they may refer you to a Speech and Language Therapist (SALT). If the person is eating too fast, remove food briefly to allow person to slow down. Allow the person lots of time to eat if they are slow.



eat by ZakaUddin from the Noun Project

Eating and drinking at the same time as the person may encourage them to eat and drink too

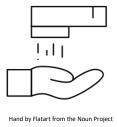
If the person is refusing food:

- If possible, **promote independence**. You could encourage the person to take part in food preparation.
- Check for unmet needs. Do they need the toilet? Are they in pain?
- If the person refuses a meal, keep it in case they want to eat it later.
- Think about how to name / present food to make it appealing.
- Offer choice or preferences.
- Try different foods and tastes.
- Offer something sweet.
- Describe what is on the plate.
- Wait until the person's mouth empty before offering the next mouthful.
- Distract the person with something else so they eat.
- Present food differently. You could try finger foods.
- Try offering smaller portions and/or snacks throughout the day.
- Try a different colour plate or a smaller plate.
- Provide food even if person says they are not hungry. Leave food out for the person.
- Offer food and drink when person awake whatever time of day.

Going to the Toilet

- If possible, **promote independence** and encourage the person to go to the toilet themselves.
- If possible and appropriate, offer the toilet regularly including during the evening and/or night and before bed.
- If the person stands up, they may need the toilet. Show or remind the person where the toilet is.
- Supervise toilet use if needed. Talk the person through the process.
- It may work to prepare toilet roll for person and take the rest away.
- Allow the person privacy while on toilet. You could leave the person on the toilet for a little while to make sure they have finished.
- If the person does not know what to do with used toilet roll, place a lined bin in a suitable position.
- If appropriate, assist with wiping the person's bottom. Get in a position where you can clean the person properly. Clean in a motion from front to back and not the other way around, as you could cause an infection. Make sure the person's bottom is clean. Wash the person's bottom if needed. If the person is likely to get sore do not use soap or scented soap, there are other products to use such as washing creams. Offer a shower or bath if the person is very messy. Use equipment, such as foam, tissues, wipes, cream or a Tena wash glove (ask the person's General Practitioner or a continence nurse for advice).
- Try to make sure person is properly re-dressed after the toilet. Assist/prompt the person to wash their hands.
- If the toilet is never used and/or the person stays in their bed you may have to use incontinence pads.
- If you provide care while the person is on the bed, obtain an adjustable height bed and adjust the height for your comfort. An Occupational Therapist could assess your equipment needs.





Try to reassure the person, as they may feel inadequate, ashamed or embarrassed

Going to the Toilet Continued...(1)

- Try to keep the person going to the toilet; if the toilet is refused, it may be helpful to use an incontinence pad and regularly check it.
- Incontinence See if you can get advice and incontinence equipment from the person's General Practitioner, a continence nurse or bladder clinic. If required, obtain suitable pads and pants (often net pants) to hold up the pad. For males, you could trial incontinence equipment such as a Womble, convene, or pads. Try to take off the worst of the faeces with the pad. Dispose of pads by rolling them up and putting them in bags, double bagging is a good idea and then place in the bin.
 - o Reassure the person it is okay to wear a pad.
 - You could remove the person's old knickers or pants from their drawers and leave pad knickers in their place.
 - o If needed, obtain cream to prevent or manage any soreness.
- If urine is limited or dark, monitor fluid intake and output.
- See the person's General Practitioner if you suspect a <u>urinary tract</u> <u>infection</u> (see box) or other problem such as constipation.
- The Bristol Stool Chart can be useful to assess bowel movements.
- If the person is constipated encourage fluids and high fibre foods, try a
 hot drink and if possible, exercise such as walking (more information
 here).



Apple by Diego Naive from the Noun Project



hot drink by Iconspace from the Noun Project



Walk by Adrien Coquet from the Noun Project

If needed, use protective sheets on the bed

Signs of a urinary tract infection (UTI)

- Signs of pain or a burning sensation when urinating
- Urine that looks cloudy or blood in the person' urine
- Needing to urinate more often, suddenly or more urgently than usual
- Signs of lower tummy pain or pain in the back, just under the ribs
- A high temperature, or feeling hot and shivery
- A very low temperature below 36C
- Changes in behaviour (confusion or distress)
- Worse than usual incontinence
- New shivering or shaking

Going to the Toilet Continued...(2)

- Males may find it easier to sit on the toilet rather than stand if they are unsteady. They could use a bottle for urine.
- Some people with dementia go to the toilet regularly. Do what's best for your situation. You may find it best to let the person go frequently, distract them or keep them busy.
- Clean toilet areas if needed after the person has used them.
- **Family carers:** You may want to wear gloves when assisting with the toilet. If things are difficult, consider having paid carers visit to provide some of the person's care.
- **Going out** -. It may be a good idea to go somewhere you know where the toilets are.
 - Ask person if they need the toilet subtly or have a signal if out that means the person needs the toilet. You may need to guide the person.
 - If you are in a café or restaurant and you leave the table to accompany the person to the toilet, let the staff know so they do not assume you have finished your meal/drink.
 - Go into public toilets with the person to help them work out how to use the flush/taps and know where to find their way back.
 - Obtain a RADAR key, a universal key for many disabled toilets in the UK (Eurokey in Europe). Available from most local authorities and many outlets online.
 - Try not to give the person laxatives or diuretics (water pills) before going out.
 - You could take a bottle for males to use.
 - o If appropriate, take spare pads, clothes, bottle out with you.
- Equipment You may need to install handrails, a raised toilet seat, obtain a commode and/or consider having a toilet flush that the person recognises. Check with the person's General Practitioner if an Occupational Therapist (OT) is available to conduct an assessment.



Before leaving the house factor in time to offer the toilet



Toilet by iconixar from the Noun Project

Catheter Care

- If possible, **promote independence** and encourage the person to maintain their own catheter care.
- Seek support from the person's General Practitioner or practice nurse.
- Make sure the Velcro elastic straps are threaded through behind the tube and leg bag rather than visible wrapped around the front side, so that the flow of urine is not restricted and can flow freely into the bag and out of the tap.
- You could swap sides where the bag sits to reduce the possibility of becoming sore.
- Try to make sure the bag is attached well.
- You could use a tissue to stop drips.
- Make sure the tap is not moved or stuck open by trousers.
- Empty the bag before you go out.
- If needed, go into a disabled toilet to help the person when out.
- Have a container such as a jug to empty catheter bag into.
- Take a container such as a bottle out with you to empty catheter bag into.
- Attach a night bag at night.
- If the catheter bag has a tap, change the bag when it is empty, and the person is sitting.
- When changing the bag, make sure it does not pull on the catheter.
- Try to learn as much as possible from NHS staff or carers.
- Try to make sure bladder wash outs are regular.
- Take spare clothes / catheter bag out with you.
- Any issues contact your General Practitioner or practice nurse.



Always ask for help if you are unsure

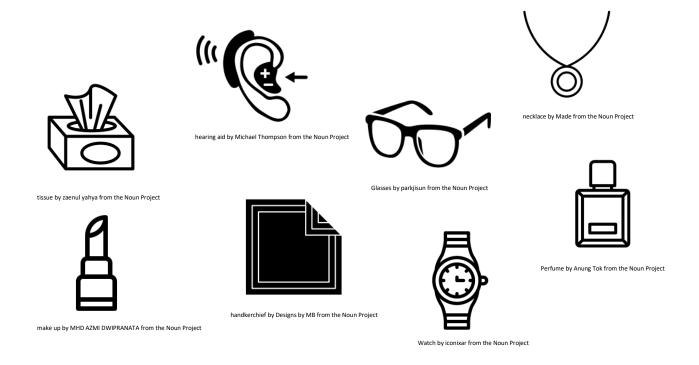


jug by Aiden Icons from the Noun Project

catheter by Gan Khoon Lay from the Noun Project

Finishing Touches - Hearing Aid - Glasses

- If possible, **promote independence** and encourage the person to maintain their own routines and appearance.
- Try to make the person as presentable as they would usually have been.
- Do not forget to use deodorant if needed. Roll on or spray could be more acceptable to the person, if one is not well received, try the other.
- Finishing touches such as adding beads or perfume/after shave can be important for the person.
- Keep glasses and hearing aids in certain place so they are easy to find. It may be helpful to have a clearly labelled box/tub for each. These could be put away at the end of each day for example inside the wardrobe.
- Does the person need a tissue/handkerchief or lip balm?
- Create a routine for the final care activities such as make up, hearing aid, watch, and glasses to make sure nothing is forgotten.
- Make sure you have items you may need with you when you go out (for example, the person's glasses).
- Try to make sure hearing aids work, they are cleaned regularly (check for wax build up) and repairs are done. Disconnect hearing aid battery at night and change batteries as needed. Check hearing aids are in in the ear properly. Remove hearing aids before washing hair and do not put hearing aids in damp or wet ears. Leave hearing aid out if ears are sore.



Miscellaneous

Walking - If possible and safe to do so, **promote independence** and encourage the person to walk. Make sure person has stick, walking frame, or something to hold on to if they are unsteady. You may want to install grab rails.

walker by Fuat sanlı from the Noun Projec

Hoist transfers – Make sure you use the correct sling for hoisting, going to the toilet or bathing.

Bed Care - If the person is restricted to their bed make sure they are rolled safely and turned regularly to protect their <u>pressure areas</u> (heels, ears, back of head, shoulders, elbow, inner knee, lower back, buttocks, sacrum, hips). Use a slide sheet if appropriate. You may need to prop the person up with a cushion or use one of the bed settings to support the person. Obtaining a rise and fall bed is advisable.

Hospital Bed by Soremba from the Noun Project

Health – Look after the person's health, if you notice anything strange try to ensure they see their General Practitioner, for example if you suspect a urine infection. Make sure the person sees a nurse if they need dressings.

Nurse by Luis Prado from the Noun Project

Environment - Adapt the environment to the person's preferences and needs. Think creatively. For example, install grab rails and clear away items which may confuse the person and/or block direct routes to the toilet. Think about colours, lighting, and noises such as the radio, TV or doorbell. Are mirrors confusing to the person? If so, remove them.



mirror by Adrien Coquet from the Noun Project

Specialist care – Learn from professionals how to provide any specialist care the person may need, such as help with a false eye or stoma.

Managing Refusals of Care

• If the person is refusing, ask yourself:

Has the person got any unmet needs?

- Check for hunger, thirst, pain, boredom, loneliness, tiredness, discomfort, sadness, toilet needs, or vision, hearing or dental needs.
- If possible, try to address any identified unmet needs.

Is the person unwell?

- Check for signs of a urine infection, constipation, fever, clamminess, or pain.
- If possible, try to address the issue and make the person feel better or seek General Practitioner support.

Is it safe to leave and try again in a little while?

• If care is not urgent or essential, try again a short while later.

Can you adapt your approach?

 Try to be calm, approach the person with a smile, hold their hand, adopt a lower position so you do not appear intimidating, promote independence, make a positive connection before attempting any care, work slowly.

Can you adapt the type of care provided for this time?

For example: Is a strip wash rather than shower appropriate?
 What about using an electric razor rather than a wet shave?
 Could you obtain clothes that are easier to put on/take off?

Are you able to seek support?

 Do you have another carer you can call on for advice or assistance? Maybe a family member of the person? Do you need to seek external support from the person's General Practitioner or social services?

Managing Refusals of Care Continued...

There may be times when care cannot be left, for example with incontinence. At these times try to use the ideas in this booklet. If the situation is very difficult seek professional advice.

- If possible, promote independence and encourage the person to carry out their own care.
- Try to pre-empt getting into difficult interactions by **adapting your approach**, the timing of care or your expectations.
- Try to accept that you may not always manage to do everything, and you may need support.
- Try to accept that the person cannot help their condition. Try to come to terms with and accept the situation. You will need to compromise if the person cannot. Some people find having a routine can be helpful.
- Know yourself and what you are capable of. Some people find it easier if they take more control of things.
- Trying to get the person to change their habits will be difficult, instead try to manage or work around their new reality and actions.
- Try to find solutions by thinking around difficulties.
- If the person is angry, try not to get in a position where you are trapped. Keep nearer to the exit of the room than the person.
- If possible, when things are difficult, get someone else to intervene.
- Try to take a break. Make time for yourself. Relieve the pressure you feel in some way some people shout, cry, exercise, or indulge in their hobbies.
- Family carers: try to get enough sleep, you may need to nap during the day.

Family carers: Seek external help if needed.

- Consider seeking support or advice from support groups, advice services such as the Alzheimer's Society or health professionals.
- Paid homecare may be one source of support. You may qualify for free care. If used, try to get continuity in paid carers, so they get to know the person you support.
- o If the situation is very difficult, consider a care home for respite or full-time care. There is no shame in getting help. Communicate with care-home staff and pass on information about the person for example, key words they respond to.

Adapting if the Person Refuses

- If possible, **promote independence** and encourage the person to carry out their own care.
- If safe to do so, leave the person for a short while and then go back.
- Do not enforce care, you may have to provide less care for a short time.
- If possible, briefly leave the care activity until the person realises the issue or is ready to continue.
- Simplify care activities.
- Adapt the person's or your routine.
- Try different times of day.
- Seek advice, speak to the person's General Practitioner for help or referral to a specialist.
- Adapt food and drink to the person's preferences or so it is easier for them to manage.
- Adapt your approach, be cheerful, quiet or slow.
- If things are difficult, prioritise the most essential care activities.

Offer a different mode of care:

- Use an electric razor rather than a wet shave. If the person has had a beard in the past and it would be acceptable, you could let a beard grow rather than shave
- Think about other means of care such as a strip wash rather than a shower
- You could try:
 - Dry shampoo rather than hair wash
 - File rather than cut nails
 - Have a dressing gown day
 - Easy to put on and take off clothes



Try to reduce conflict. Talking to others may provide some ideas on moving forward.

Acting to Prevent Refusals of Care Occurring

- If possible, promote independence and encourage the person to carry out their own care.
- Start care when you have time.
- Take your time.
- Make sure the person is comfortable.
- Try to make sure person is calm before starting care
- Try to look for unmet needs. Is the person wearing their glasses? Could they be constipated? Are they in pain? Do they have any new bruises suggesting they hurt themselves somehow? Are they cold?
- Try to assess the person's mood before starting care, look for cues/clues.
- Position yourself so you are not intimidating to the person.
- Care homes/paid care: would the person prefer a male or female?
- Use visual cues to prompt the person.
- Warm the room/person's clothes.
- Learn about person and their preferred/usual routine.
- Knowing the person could be key. Perhaps have a <u>This is Me</u> form completed or conduct some <u>life story work</u>. A This is Me form is useful to send with the person if they ever go to hospital.
- Use your knowledge of the person to distract them.
- If it may help, have music playing in the background or sing as you help the person.
 If possible, overlook small issues
- Remove any known triggers.
- Keep the person safe and covered as much as possible (you could put a towel on their lap) for dignity.
- If it is safe to do so, leave the person for a little while then go back.
- Use trial and error to see what fits your situation.



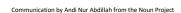
Family carers: you might try
to conduct your own
personal care at the same
time as person for example
clean your teeth together.



Optimising Communication

- If possible, encourage the person to tell you their care needs and wishes.
- Let the person know about the care in plenty of time (unless this is a cause of worry).
- Explain, demonstrate, talk through the activity, build trust.
- Reassure the person throughout.
- Prompt and encourage.
- Move physically down to the person's eye level, speak to the person clearly.
- If appropriate, use humour laugh with the person, use in-jokes and shared experiences, and build rapport.
- Minimise sound of activity by using words like 'just' and 'quickly' make the care activity sound positive.
- Talk about what you are going to do after the care activity to distract and give the person something to look forward to.
- Try not to ask questions about care which can only be answered by 'yes' or 'no' if the person will always say no.
- It may be helpful to let the person think the care activity is their idea or that they are in control.
- It could be useful to offer simple choices this or this?
- Do what works in your situation. It may be best to either go along with the person's reality or to orientate the person to what is happening.
- Draw on your existing relationship and knowledge about the person.
- Find out how the person is check the person is okay.







Communication by Oksana Latysheva from the Noun Project

Work in partnership: when talking to the person with dementia about a care activity use the word 'we' to create togetherness.

For example, 'shall **we** go to the bathroom?'

Optimising Communication Continued...

- It may help to keep language short and simple, do not overcomplicate what you are saying, but try not to sound patronising.
- You could try talking about something the person likes.
- Saying please may help.
- Try not to use key trigger words such as bath / shower.
- It may help to point out the benefits / positives of the care or consequences of not doing the action.
- Relate the person's actions to your own experiences. "I know how that feels...".
- You may have to ask in several ways to gain understanding.
- It could help to repeat instructions.
- Answer any questions.
- If appropriate, use a care plan and make sure it is up to date.
 Record/document/ handover to paid carers, family members, other carers.
- Involve the person if possible.
- Give the person power over the activity if possible.
- Make sure hearing aids are in and working.

Communication by ProSymbols from the Noun Project

Non-verbal communication

- Touch to show the person where you mean
- Demonstrate care activities to show the person what is required
- Use eye contact
- Get down to person's level
- Go at the person's pace
- Go in happy and positive smile
- If appropriate, cuddle / hug
- Use a calm approach

General Strategies for Assisting with Care

- If possible, **promote independence** and encourage the person to carry out their own care.
- Prepare for the care activity get everything ready before starting.
- Do what feels right each day depending on your mood and the person's.
- Find out how the person is look for cues from the person.
- Check with the person that your approach is okay.
- Try not to worry about small things.
- Build up familiarity with the person and their routine.
- Do as much as you can if the person is distressed or upset.
- Explain what and why you are doing things.
- Make time for the person.
- Compromise with the person.
- Find some common ground with the person.
- Do what works for you. You may find it helpful to enter the person's reality or try to orient the person to the here and now.
- If relevant, try to reduce the person's anxiety.
- Gently take more control of the care activity if you cannot cope with not knowing if it is completed properly.
- Be honest with the person.
- Give the person some space.
- If possible, offer the person choice.
- Try to be patient with the person.
- If appropriate, use humour.
- Try to pre-empt any difficulties.
- Use threat reduction strategies soft tone of voice, approach person from the side, try not to lean over the person.

Change your approach if it does not seem to be working. A successful approach depends on the person and what they are like that day.

- Adopt a problem-solving approach try to think creatively.
- Try to use a calm approach.
- Adapt to the person's needs and preferences.
- Try to let go of the non-important things.
- Use a positive approach.
- Most caregivers use a mix of approaches.



caring by Tinashe Mugayi from the Noun Project

Reassure the person throughout

Solving by Vectors Point from the Noun Project

Coping Mechanisms: Ideas from Family Carers for Family Carers

Spend time coming to terms with the situation-gaining perspective- adapting.

- If you are ready, learn about the situation and the person's condition.
 - For example, FutureLearn online, Google, contact your local Alzheimer's Society (links at the end of the booklet).
- Try to come to terms with and accept the situation. Get used to the person's condition the new normal. This may take time.
- Think back to how the person has enhanced your life.
- Social comparison family carers found that there was always someone worse off.
- If possible, draw on the support of family members/friends.
- Try not to dwell on the situation.
- If you believe, you could use morning prayer to start each day anew.



Develop personal mechanisms to cope – what works for you?



Fist by Becris from the Noun Project

Try to obtain external support:

- Think about getting someone in to sit with the person for a little while, so you can have a break.
- Speak to your General Practitioner.
- Consider using paid carers.
- Network with other carers.
- Join community groups.
- You could use a day centre.
- Try a dementia café.
- Call on a neighbour a different face can be helpful.
- Consider respite care.
- Contact a befriender maybe via Age UK.
- If things are very difficult, consider your options for support.



meditate by Becris from the Noun Project

Family carers were sometimes keen to keep busy to occupy the person and fill the time.

Coping Mechanisms: Ideas from Family Carers Continued...

Family carers found it helpful to let off steam (if possible, away from the person):

- Have a cry.
- Swear / shout.
- See your friends.
- Get out of the house.



Try to put yourself first at times

- Go for a ride in the car.
- Get away a break a holiday respite.
- If safe to do so, walk away from the person for a little while.
- A brief mild disagreement may relieve the pressure.
- Try to power nap.
- Speak to your doctor if you cannot cope. For example, if you are having trouble sleeping.
- Have 'me' time a hobby:
 - Gardening
- Cooking
- Shopping
- Computer games / puzzles
- Dog walking
- Walking



dog walk by Gan Khoon Lay from the Noun Project

Some family members felt reluctant to be a carer.

Try to make things easier:

- Some daughter or son carers had the person with dementia move in with them to save travelling back and forwards to their home.
- Takeover the monitoring of tasks to make sure they are completed.
- Be in control keep dangerous things away from person.
- Create a routine.
- If appropriate, use paid carers.
- Try to obtain any care equipment you may need.

In our study, at times family carers just had to forge on – they felt they had:

- No choice but to cope
- To just do it

Coping Mechanism: Ideas from Care-Home Staff for Care-Home Staff

Support

- Try to draw support from the staff team comradeship.
- Discuss approaches / ideas with the wider staff team.
- If things are difficult, see if you can swap with another staff member.
- Go back to the person later.
- Go to the person with a colleague a 'double up'.
- Shadow a colleague who knows the person well.
- Use the care staff team for ideas / support.
- Document care not completed / any refusals.

Letting off steam

- Walk away from the person for a little while.
- If necessary, have a cry in private if possible.
- Talk to your work colleagues.
- Take a short break.

General care home tips for staff:

- Use a whole team approach.
- Acknowledge the routine drive to get everyone up but try to make time for each person.
- Communicate with other staff members.
- Use a professional approach.
- Always hand over and report information.
- Always read care notes to find out about the person, especially with new residents.

Adapting to the person

- Learn about the person's condition and routine.
- Find out the person's life, preferences, likes and dislikes.
- Develop a relationship with the person.
- Use humour if appropriate.
- Change your approach to the person.
- Try to display a cheerful disposition.



team by Med Marki from the Noun Project



Safety

- Keep yourself safe. For example, if the person is angry, position yourself between the person and the door.
- Have documentation such as medication records ready for paramedics.
- You could provide a picture of the person to the Police in-case they go missing. See if the Herbert Protocol is running in your area.
- Call emergency services if the situation is dangerous.
- Never be frightened to ask for help whatever situation you are in do not struggle alone.



Safety by Pavitra from the Noun Project

The responsibility is with

the caregiver to adapt

when the person cannot

Caregiver Development

- Learn about the person's condition.
- Learn how to conduct essential care activities.
- Learn about the person and their life.
- Make sure medical check-ups happen such as medication reviews.
- Question the person's General Practitioner if you do not understand or agree with their approach.
- Learn from previous encounters and change care going forward.

Difficult Care Situations: seek help

Sometimes caregivers struggled and acted in the following ways:

- > Threatened the person with consequences, told the person off.
- ➤ Nagged told the person they had got to do something.
- ➤ Just carried on or told the person this is what we are doing or told them to do it by themself.
- Showed frustration / got angry, yelled.
- > Showed the person they were upset / tearful.
- Confronted the person.
- Restricted the person's actions.

Conflict by Chintuza from the Noun Project

If you find yourself acting this way or in conflict with the person with dementia it may be a good idea to seek support or help:

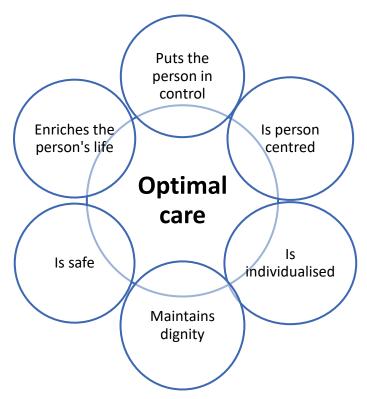
Alzheimer's Society dementia-connect-support-line

UK. Tel: 0333 150 3456

Try to manage any difficult emotions.

Remember that behaviours are usually due to the dementia and not the person; behaviours are seldom personal.

Caregivers' Thoughts about Optimal Care:



Advice from Caregivers

- Promote independence.
- Involve the person.
- Take time do not rush the person.
- Try to have a calm approach.
- Create a calm environment.
- Learn and exchange information about the person and their condition / type of dementia (if you feel ready to do this).
- Use cues from your surroundings to stimulate chats with the person.
- Inform other carers what person has been / is like.
- Do not patronise the person.
- If possible, do not get too close to the person's face.
- Approach the person with a positive attitude.

 Use trial and error and assess the person's response to inform how you next act.

• Assess the person for changes or clues of any issues.

- Play gentle music in the background.
- Enter the person's reality.

Patience Empathy Tolerance Acceptance



meditate by Becris from the Noun Project

Advice from Caregivers Continued...

- Learn about dementia.
- Have patience explain / answer and then re-explain / answer.
- Listen to the person.
- Consider some training maybe a simulated experience of dementia.
- Learn from others.
- Try new techniques.
- Understand behaviours and actions are likely to be the disease not the person.
- Get down to the person's level, do not stand over them.
- Offer choice if possible.
- Try not to lose your temper.
- Avoid confrontation.
- Be kind.
- Do what is in the person's best interest.
- Adapt to the person and their needs.
- Enrich the person's life.
- Divert or distract the person if they are distressed.
- Talk to the person.
- Find out about the person and their needs.
- Give the person space.
- You may find it easier to not mention the care activity until you are going to start it.
- Look after yourself try to relieve any pressure you may feel.
- If appropriate, use humour.
- If possible, involve the person's family.
- Collaborate with other carers 'double-ups'.
- Consider visiting a dementia café or other community service.
- Create routines, rituals and habits to get things done.

Try to come to terms and cope with each new change – gradually adapt. This may take time.

Understand behaviours and actions are likely to be the disease not the person



support by Andre Buand from the Noun Project



routine by Adrien Coquet from the Noun Project

Sources of Support

General

- The person's General Practitioner (doctor)
- Local community groups, carer groups, dementia cafes
- Apply for a needs assessment from Government/local social services
 England/Wales
- You could find out about Teepa Snow and her Positive Approach to Care
- Resources available from <u>The Global Dementia Knowledge Exchange</u> <u>Platform</u>

England, Wales and Northern Ireland

- Alzheimer's Society Dementia Talking Point an online community
- Alzheimer's Society <u>Dementia Connect</u> support telephone line 0333 150 3456
- Alzheimer's Society <u>Find Support Near You</u> an online directory
- Alzheimer's Society Cymru (Wales)
- Alzheimer's Society Northern Ireland

Scotland

- Alzheimer Scotland
- Alzheimer Scotland Dementia Helpline 0808 808 3000
- Alzheimer Scotland Find Support Near You an online directory

UK

- <u>Dementia UK</u>
- Dementia UK Get Support
- Dementia UK Helpline 0800 888 6678
- Age UK

Other countries: Search online for dementia or Alzheimer's organisations in your country. For example:

United States <u>Alzheimer's Association</u> helpline 800.272.3900 Canada <u>Alzheimer Society</u> Australia <u>Dementia Australia</u> helpline 1800 100 500 France <u>France Alzheimer</u>







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