

Looking After Someone Who Is Confused *A Carer's Guide*

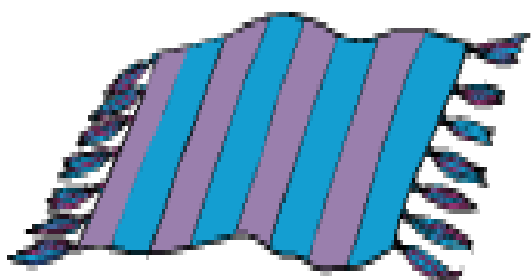
This booklet has been written to help those looking after people who have major memory and concentration problems, usually as the result of a brain illness or brain injury. We have used the word 'confused' to describe these individuals, although this term often means different things to different people. By 'confused', we would include difficulties such as – cannot remember what is happening from one day to the next, and often from one minute to the next; repeatedly asking the day of the week; getting lost easily and frequently in very familiar places; and not being able to do even simple tasks around the home that were once easy to do. This booklet suggests ways in which a carer could help someone with confusion remain safe and cope better in everyday situations.

Safety First

- Make a note of potentially risky areas for the person, such as in the bathroom or the kitchen. If there are any hazards, try to reduce the likelihood of harm, or remove the hazard where possible.

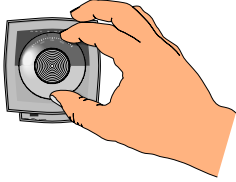


- Put away things that could be dangerous or cause harm, such as sharp instruments, power tools etc.



- To reduce the risk of falls, make sure that floor coverings are secure and that mats are not frayed. Make sure that things are not left lying around on the floor and keep floors dry. If necessary, reduce the amount of furniture that is around.

- Turn the thermostat on the water heater down to reduce the risk of the person scalding him or herself.
- If there is an open fire, or heater with exposed elements, always use a fireguard.



- If there is a danger that the person may take too many tablets at once, use a pillbox with different compartments and only put out enough medicine for one day at a time. A pillbox will also help the carer to recognize when medications have been taken or missed.

Be organised

- Make sure that the place where the person lives is tidy and well organised, with items in fixed places. Keep things such as clothes, items in the kitchen, items in the bathroom, etc in the same, regular place.



- Put labels or pictures on cupboards or drawers to give the person an idea of what is inside. You can also put labels or pictures on doors of particular rooms, for example, the bathroom. Make the labels or pictures large enough so that they are easily seen. If some doors have distinctive colours, this may also help the person to remember what the room is used for.
- For some activities such as dressing, making a simple meal or drink, using the phone, etc you may find that you have to make up an 'instruction sheet', with the steps of what to do clearly written out and displayed in a handy place.
- Have a wall calendar or fridge whiteboard to manage activities

Have a regular routine



- Try to keep to a regular routine each day, with things happening at the same times each day or each week. This will help to avoid situations where the person may forget to do something. The timing of events and activities is not as important as the order in which they occur. For example, if the person always gets out of bed, has breakfast, then bathes and dresses, it is not a good idea to change the routine and have them get out of bed, bathe and dress and then have breakfast.
- Get to know when the person's 'best time of day' is. This will often be in the morning, when they are feeling fresh, but if they do not sleep well it may be later in the day. Where possible, try to arrange appointments, visits and other activities during their best time of day.
- Plan activities that are of short duration and include breaks. Try not to do too much in one day, since you may find that the person tires easily.
- For some activities such as dressing or making a simple meal/drink, you may find it useful to make up an 'instruction sheet', with the steps clearly written out and displayed in a handy place.

Keep the person oriented



- If the person is always asking the time of day or day of the week, consider placing a day-date clock in a prominent place and remind them to look at it. Clocks displaying only the day of the week are also available.

- Alternatively, if he/she wears a watch with the day and date displayed on it, prompt the person to look at their watch.

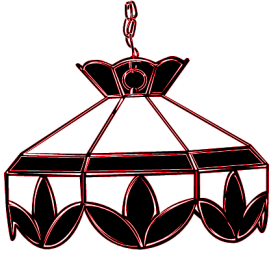


- When the person has a rest during the day, sit them in an easy chair or sofa rather than in bed, so that when they wake up they know it was from a nap rather than a night's sleep. If the person is resting near a window, the daylight will also help orient them to the time of the day.

- If the person keeps asking for information such as where they are, this could be written on a white-board in large, clear lettering and put in a convenient, easy-to-see place. If the person has a weekly schedule for things that are done on certain days, have this schedule clearly displayed. You can also use a white-board to write down important events for each day, or about particular things that are going to happen in the future, e.g. people who are due to visit.
- If there is a safety checklist for things to be done last thing at night, have this displayed in a prominent place in the person's bedroom.
- In some situations, it may be useful to have information readily visible to the person on a wristband. For example, if the person repeatedly asks for information such as what is wrong with them or where they are, they could be told to look at their wristband. Their address and home telephone number could also be written there in case they get lost.



- Try not to tell the person about things that are going to happen too far in advance. People who are confused may have problems planning ahead. They may become upset or worried if they think they have missed something or will forget something.



- Leave a light on in the hallway at night. Waking during the night and not being able to see anything familiar can be quite frightening, particularly for someone who is confused.
- If you are going out, write a note saying where you are going, with a contact name, address and telephone number. Put the note in a prominent place where it will be clearly seen.
- Most people who are confused may be unable to use a standard mobile phone, but simpler phones are now available. If the person is using a mobile phone, you could try and programme reminders that go off at key times, or send them text messages as reminders. In the case of land-line phones, 'photophones' which have pre-dial buttons with photographs of the person being called are also now available.
- It may be useful to keep a 'memory book' to record important events that have happened each day. You could consider inserting some photographs of outings. The front or back of the book could also contain information that is needed in an emergency. Encourage the person to look at this memory book each day as part of their routine. If you think the person is interested in the news and can take in the information, then you could give them a daily newspaper of their choice, or have a TV news channel regularly on.

Feeling useful and valued is important



- Enabling the person to help out with simple tasks around the house such as dusting, setting the table, sorting the laundry, or watering the garden, may give them a sense of purpose.

- Exercise is also important, so if possible try to take the person out for a walk or some other form of exercise (e.g. swimming) at least two or three times a week.



- Encourage skills and activities that are easy and pleasurable for the person to take part in. Consider past hobbies or interests that they were good at, listening to music they like, watching videos that engage their interest,

looking at familiar photographs, or being in the company of children or pets in a safe setting. Having a favourite piece of music in the background may help to make the person feel better. In some instances, this may help calm them and make them more co-operative.

- Do things to remind the person that they are valued and loved, even if this just means touching and embracing them from time to time.



- Have a pencil and notepad or Post-It Note Dispenser near to the telephone so that the person can write down any messages that he or she receives. It may be useful to also have a prompt card stuck somewhere, with key advice such as – **‘Write all messages down. Tell the caller that you are writing the message down. Ask the caller for their name and telephone number. Read back the message to the caller’.**

Handle conversations carefully

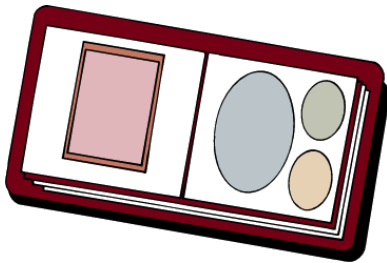
- People who are confused may have problems in understanding what has been said to them or in remembering what they have been told. You may find yourself needing to repeat something several times or having to write things down. Although often frustrating, try to be patient and understanding when repeating information.



- The conversations that you have with the person may, on occasions, be 'muddled'. If what they say does not make sense, gently try to change the topic to something the person finds interesting and meaningful. If the patient insists on you saying something in response, it is best to try to give a neutral reply.
- If, during a conversation, the person becomes angry or upset, try to distract them rather than argue with them.
- In general, try to follow three rules – avoid asking questions, generally agree with what the person is saying, and try not to interrupt the person during a conversation or while they are doing something.
- If the person is erroneously re-living a period in the past, or making up events that have happened or might happen ('confabulation') it is usually fine to go along with that rather than confront the person with the reality of the present. You need not feel guilty about doing this. Try to address any concerns that underlie the confabulation. Try to cover the topic indirectly from another angle. It may help to distract the person to other topics or activities they find interesting and enjoyable.

- When you say something, keep the information short with one item at a time. If it is a request or a message, ask the person to repeat it back in their own words to make sure that they have heard and understood it properly.

Make good use of past memories



- 'Confused' people may have difficulty remembering some of their past and may also be uncertain about the identity of close family members. One-to-one interaction with familiar family members will help. If that is not possible, keeping familiar items, such as family photographs or family members' personal belongings around them may help. In some instances, it may be helpful to play a video of a past family occasion where the person was present, and which they remember and relate to.
- If the person is regularly asking about relatives or friends, especially if they are unsure whether the person is still alive, it may help to have photographs on view (e.g. on a wall or mantel-piece), with names and ages written if necessary.
- Try not to keep 'quizzing' the person in an attempt to test their memory. For example, asking 'Do you remember her?' 'What is her name?' and so on. This can make the person feel anxious or that they have failed. It is best just to indicate the person's name to gently remind them.

Stay calm and in control when dealing with outbursts of anger

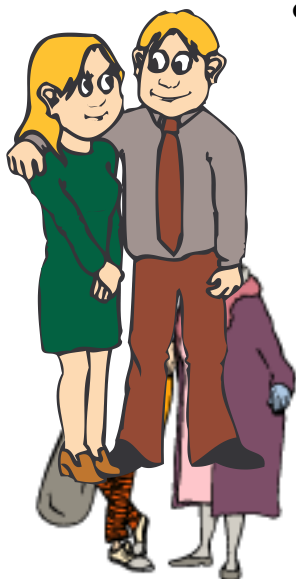


- The person may feel angry about the situation they find themselves in. Do not take this anger personally – it is always easier for the person to ‘lash out’ at someone close, even though that person is not the cause of their anger.
- Try to find out if there is any pattern as to when and why anger outbursts occur. By identifying and avoiding situations that lead to these outbursts, you may be able to prevent their occurrence.
- If possible, distract the person's attention towards another activity that they find interesting or calming, or remove the person from the upsetting situation.
- Be calm and firm - encourage and support the person to use more positive ways to deal and cope with similar situations.



- If there is an outburst of anger and you are unable to determine the cause or to distract the person, try not to retaliate. Instead make sure that the person is safe from harm and leave them alone to calm down. When you return, the outburst will probably be over, and they may have forgotten the trigger for their anger.

Prevent the person from wandering



- Sometimes people wander because they feel uncertain and disorientated in a new or unfamiliar environment. Giving them extra help in finding their way around and plenty of reassurance may be all that is needed to help in this situation.
- If a person has poor concentration, they may become easily distracted and also more likely to wander.
- Some wandering may also occur due to loss of short-term memory. For example, the person may go off to the bathroom, and simply forget where it was they were going.
- People sometimes wander off searching for someone or something related to their past. The best way to deal with this type of wandering is not to reason with the person but instead gently distract their attention and bring them back home.
- Another, often overlooked, reason for wandering is that the person is in some sort of physical discomfort or pain that is eased by walking. It is important therefore, to try and find out if they are experiencing any physical problem or pain and to remedy it if possible.
- It is usually wise not to confront a person who is determined to leave the house, as they may then become very upset. Instead, try accompanying them a little way and then diverting their attention so that you can return home together.
- If a person does wander off alone, try not to show anger or anxiety when you do find them. Reassure them and try to get

them back into familiar surroundings and into a familiar routine as quickly as possible.

- Ensure that the person has details of their home address and a contact phone number with them at all times. Where possible, providing them with an easy-to-use mobile phone for use in situations when they are away from home, will help with keeping in touch.
- Make sure that friends and neighbours are aware of the possibility that the person may wander off so that they can help to keep an eye out for them.
- Electronic alarm systems that will trigger when someone approaches a door or when a door is opened are available on the market. These can give you an early warning that the person is about to leave the house. There are also companies that offer tracking systems which can help you to locate someone.

Don't be too hard on yourself



- Feeling angry or upset are natural responses to stressful situations. Don't be too hard on yourself if you feel angry as a result of the stresses and strains of taking on the role of carer.
- Expect a certain amount of family conflict during the time that you have a confused person to look after. Each family member will experience different emotions and will have different demands placed on them when someone else in the family is confused. Try to make time for each other and to talk through any problems together.

- Gently introduce any unfamiliar helpers to the person suffering from confusion and try to establish a routine with that new helper.



- If there is anything that you do not understand about the person's memory loss, their illness or the treatment that they are being given, don't be afraid to ask a doctor or other professional.

- Remember that you are not alone. There are a number of support groups and other organizations that can give you help and advice and provide a 'listening ear'. Nursing staff and other care workers will be able to give you details of these groups and organizations.



- Finally, remember that being the relative, carer or friend of a confused person can be stressful. If you can get help with domestic or other activities, then do accept that help! Most importantly, be sure to take care of your own health. Schedule 'time out' to have a break and remember to look after yourself!

RESOURCES ON THE INTERNET

There are a number of websites that provide helpful information on looking after someone who is confused, where to buy memory aids, etc. A listing of these can be found on –

www.londonmemoryclinic.com

Please keep in mind that this booklet is not meant to be a substitute for professional advice or treatment.