



Easter Seals

Creating solutions, changing lives.



Transportation Solutions
for Caregivers:

A Starting Point



Introduction

to Easter Seals' Transportation Solutions for Caregivers

Caring for a loved one is often as challenging as it is rewarding and can affect both work and family life. Transportation can be especially taxing and time consuming. According to an AARP survey of family caregivers (1997), eight out of ten caregivers reported helping with transportation.¹ In a survey on community transportation by AARP (1997), two thirds of non-drivers who were surveyed reported getting rides from family and friends to get where they need to go.²

The difficulties encountered in the area of transportation, such as handling a wheelchair or other assistive device, agitation, and distracting behaviors, may cause some family caregivers to stop transporting their loved ones or only transport them for the most essential appointments.

Over time, this can lead to frustration and eventually isolation for both family caregivers and their loved ones.





Family caregivers often rely on trial and error to solve their transportation challenges. This booklet and accompanying video provide tips and safe, creative solutions, devised by both family caregivers and professionals, that are designed to ease transportation challenges.

Solutions to Transportation Challenges

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Although transporting an older loved one who requires physical assistance or has dementia can present a challenge, it doesn't have to be a struggle. Often, caregivers must try multiple strategies and find that what works today, may not work tomorrow. However, there is almost always a solution and a way to make every car trip easier. Caregivers are also encouraged to seek out other people who are caring for older loved ones through local groups or via the internet (see pages 15-20 for resources). Sometimes the best solutions to challenges are discovered through learning from each other's experiences.



Communication

Interaction between you and your family member

Communication is the interaction between you and your loved one. As a caregiver, you are often in a position to set the stage for good communication. The major obstacle to effective communication is our natural tendency to judge, evaluate, approve or disapprove of the statements or actions of another person. When communication becomes emotional, as it often does among family and people close to us, it is even more important to make an effort to stay calm. Remember that our tolerance and understanding can be limited by anxiety or frustration.³

Principles of Good Communication

- Use positive and helpful body language.
- Speak directly and clearly to your loved one.
- Be patient.
- Allow plenty of time for a response.
- Do not interrupt.
- Keep directions simple by explaining them one step at a time.
- Use easy to understand language.





- Don't overwhelm the person with too much information.
- Be calm, or at least attempt to appear calm.⁴
- Empathize. Try to put yourself in his place, so that you can see their point of view.
- Avoid argument and criticism. This puts others on the defensive.
- Ask questions. Encourage your loved one to talk, and show that you are listening.⁵

If Your Loved One Has A Hearing Impairment

- Face your loved one when you speak.
- Lower the pitch of your voice.
- Do not over-articulate.
- Rephrase your statements for clarity.
- Allow enough time for a response.
- Don't shout. Shouting raises the pitch of your voice. Older people more often lose the ability to hear higher pitches than lower pitches.⁶



Sensitivity

Understanding the changes associated with aging

Older persons are not disabled because they are old. However, the aging process may result in disabling conditions.⁷ These conditions may reduce physical strength and stamina, so it is important to try to be understanding and patient. It helps to be aware of the changes associated with aging when caring for an older adult. Many of the human body's functions are affected by aging, resulting in problems with vision, balance, and pain, and can create transportation challenges.



Vision Impairment

When transporting someone with a vision impairment, it is good to explain exactly what you are doing and why. If he uses a cane or dog guide, always lead by standing on the opposite side of the cane or the dog and stay one-half pace ahead.⁸ Ask if he would like assistance before providing it. If possible, have him exit from the non-traffic side of the car, and try to be specific when giving directions on the first visit to a location (i.e., to your right/left, approximately 100 feet, etc.)

Problems with Balance

Loss of muscle strength and coordination, arthritis in the knees and ankles and changes in the inner ear all hinder balance – especially as people age. This can make getting in and out of a car and positioning in the car difficult. Allow someone who has problems with balance plenty of time to enter and exit the car. It may



take a few extra seconds for him to gain balance when moving from a sitting to standing position. ⁹

Pain

Older adults experience pain from a multitude of conditions – some short term, some periodic, and some chronic or long term. For example, people with joint pain, such as arthritis, may find it painful to enter and exit a vehicle. To be sensitive to this, give your passenger extra time and provide assistance with a gentle touch. Additionally, people with dementia can become agitated due to pain, especially if they cannot verbally communicate what they are feeling. If asked a yes or no question about this, they may be able to tell you whether they are experiencing pain. ¹⁰

Seizure Disorders

Seizure disorders, such as epilepsy, are not necessarily age related. However, older persons can have seizures secondary to certain age related conditions or diseases. The Epilepsy Foundation of America offers the following recommendations for handling a grand mal seizure:

- Do not try to restrain your loved one. Let the seizure run its course.
- Clear the area around him and try not to interfere with any movements.
- Don't force anything between his teeth. If his mouth is already open, you can place a soft object such as a handkerchief between his side teeth.
- Call a doctor if it is followed almost immediately by another major seizure or if it lasts for more than ten minutes.
- When the seizure is over, let him rest if needed. ¹¹



Preventing Agitation

Strategies to reduce agitation

While empathizing with your loved one fosters good communication, it also can prevent agitation. The following are some tips to help reduce agitation:

- Encourage reminiscence. Recognize that repetition can suggest important feelings about certain topics and ask about the feelings behind the memories. Sharing memories can be a rewarding experience for both you and your loved one.¹²
- Try to be patient and not rush your loved one. He may not understand what is happening and could become agitated. Be mindful that body language often speaks louder than words and that he will likely respond to your body language.
- When you are going to a new place with your loved one for the first time, try to call ahead and find out which entrance to use. This way you can avoid getting in and out of the car multiple times.¹³
- The environment of the vehicle can be a cause of agitation, especially if the person whom you are transporting cannot communicate discomfort. Assess the temperature, keep the vehicle clutter-free and try to reduce glare on bright days.¹⁴
- Be prepared with relaxing music, sunglasses, photos or food in case they are needed during the ride.



- Suggest that your loved one use the bathroom before each trip. Having to use the bathroom during transport can cause agitation – especially if your loved one cannot express this verbally.
- Avoid arguing with your loved one whenever possible. It is often less frustrating to try to go along with what he believes than trying to convince him of what is really happening. ¹⁵
- When communicating with an older adult with Alzheimer’s disease or related dementia, it is important to stay calm. Your loved one’s behavior is often a reflection of your own.
 - ❖ Speak clearly in a calm and respectful tone of voice.
 - ❖ Make eye contact whenever possible.
 - ❖ Give brief, clear directions (step by step if necessary) to avoid confusion. This may need to be approached in different ways until you find what works best.
 - ❖ Show your loved one what you would like him to do.
 - ❖ Avoid asking the questions, “Do you understand?” and “Don’t you remember?” Such questions can be frustrating and embarrassing to your loved one.



Dealing with Agitation

There are ways to handle agitation if it does occur

Agitation or the attempt to leave the vehicle may be the result of a desire to meet former obligations that no longer exist, lack of awareness of current surroundings while desiring to perform another task, or an inability to communicate basic needs.¹⁶ If your loved one becomes agitated, resistive or argumentative because of a belief that he should be going somewhere other than your destination, it is often helpful to agree and act as if you are going along with his plan – even use it as a discussion topic – while you actually are proceeding with your original plan and destination.

This approach, as opposed to arguing, disagreeing or re-orienting, is called “Validation.” In other words, you are validating your loved one’s beliefs, leading to more cooperation.¹⁷ For example, ask your loved one why he does not want to get in. If he can tell you what he believes is happening, “validate” his belief by going along with the story and incorporating the need for the car ride into the story. This is usually more effective than arguing with someone with dementia, as he may not have the ability to understand the reality of the situation even after many attempts on your part.

If your family member becomes agitated or resistive while attempting to enter the car or during the ride, try to determine the cause of agitation – especially if it might stem from a situation that happened prior to getting in the vehicle. Next time, you



could try going for a brief walk together before entering the car, allowing time for him to calm down. Sometimes agitation can stem from forgetting how to enter the car. Patience and simple directions may be enough to diffuse the situation.

Seat your loved one in the rear passenger-side seat so that the steering wheel is out of reach and he is not directly behind you. This way you can avoid being startled from behind when you are driving.

If your car has child safety locks, it's always a good idea to have them on – allowing the rear door to be opened only from the outside. This will ensure that the door cannot be opened by your loved one while the car is moving. Using a seat belt buckle cover (listed on page 15 of this booklet) can discourage unbuckling the seat belt during your ride.

If agitation persists during the ride, try playing relaxing or favorite music. Also, it may be helpful to offer an activity such as a photo album of family (e.g., good conversation starter), a book, candy, or a magazine to decrease agitation or distracting behaviors.

Transportation: A Review

- Ask your loved one to use the bathroom before getting into the car
- If possible, have a cellular phone in the car
- Be patient and allow time to get ready and get into the car
- Be prepared with relaxing music, sunglasses, photos, food, etc.
- Try and allow your loved one to calm down before entering the car
- Seat your loved one in the rear passenger side seat with seat belt on and child lock in the 'on' position
- Try to keep glare to a minimum
- Stay calm
- Use "Validation" whenever possible
- Give brief, step-by-step directions
- Give information in small bits
- Encourage reminiscence
- Be aware of your body language



Providing Physical Assistance

When helping your loved one, use proper body mechanics

Whether helping your loved one into the car, transferring from a wheelchair to the car, or handling a wheelchair (or other device such as a walker), it is important to use proper body mechanics. Most muscle strain injuries to both the caregiver and care receiver are preventable.

Body Mechanics

- Plan the lift – check the area for slippery spots or possible tripping hazards. Wearing appropriate footwear, non-skid heels and soles will be safer for both you and for the person whom you are assisting.
- Use proper stance – spread your feet to a width that feels comfortable to you, usually shoulder's width apart.
- Keep your head and upper body as upright as possible.
- Lower your hips to the height of the object you intend to lift by bending your knees and hips rather than your back.
- Carry weight as close to your center of gravity as possible.
- Get close to the object you plan to lift. Bear weight on your forearms rather than your hands.
- Lift with your legs.
- Do not attempt to lift with your back alone.
- When lifting, do not rotate your spine; shift the position of your feet to turn (pivot).





- Know your limits.
- Push or pull an object instead of lifting whenever you can. 18

Wheelchair Transfers

When transferring and positioning from a wheelchair to a car:

- Have the person you are helping wear a gait belt, if one is available (listed on page 15 of this booklet).
- Open the car door.
- Stand with your back to the inside of the car door and pull the wheelchair toward you – between the car door and seat.
- Talk your loved one through the transfer process step by step so that he can assist if possible.
- Hold on to the gait belt and help him to a standing position – using your legs to pull up for strength.
- Have your loved one lean weight forward toward you and put his arms around your shoulders (not your neck), if possible.
- Carefully pivot yourself and your loved one so that his backside is toward the inside of the car.
- Help him sit on the seat with his legs still out of the car – be careful that his head clears the door frame while he is sitting down.
- Once sitting and given a moment to gain balance, help move his legs into the car (a swivel cushion is helpful for this and is listed on page 16 of this booklet).
- Assist with the seat belt and close the door before going to the drivers seat.



Providing Physical Assistance *(continued)*

When helping your loved one, use proper body mechanics

Positioning

Make certain that your loved one's seat belt is securely fastened while in transit and that he does not unfasten it until the vehicle has come to a complete stop. Provide assistance when he enters or exits the vehicle, but do not make him feel rushed. Give your loved one extra time to do what is needed.

If your family member has had a stroke and has right-sided or left-sided hemiplegia, weakness or neglect, seat his affected side nearest the door (i.e., if left-sided weakness, seat on driver-side of back seat). This can aid with balance and allows you to position the weak side into the car and also encourages your loved one to assist. The seat belt with shoulder strap can be of great help with balance in the back seat. It may also be beneficial to keep a pillow in the car for positioning.



It can be difficult to assist someone who has had a stroke or has limited movement or understanding to get positioned comfortably in the car, especially if he cannot assist. A few helpful ideas:

- Have your loved one wear a gait belt for a secure place for you to hold while assisting.
- Use a swivel cushion (listed on page 16 of this booklet) to make it easier to swing his legs in while in a sitting position on the car seat.
- Place a towel on a plastic bag on your cloth seat or directly on your leather seat. Then, help your loved one sit on the towel covered seat. Next, go to the other side of the car and pull the towel toward you to slide him further into the car. Finally, pivot his legs into the footwell of the car.





Resources for Caregivers

Helpful Products, Web Sites, Assistive Devices and Equipment

Helpful Products, Assistive Devices and Equipment:

Beasy Transfer Board

Transfer from a wheelchair to a car without lifting.
www.dynamic-living.com/beasy_transfer_board.htm

CarCaddie™

Support as you get out of the car.
www.dynamic-living.com/car_caddie.htm

Chair Topper®

Automatically folds and stores a conventional folding wheelchair inside a watertight, fiberglass cover that mounts on top of your vehicle.
www.braunlift.com/pages/consumer/l700x.html

Companion Seat™

Helps people who have difficulty walking to get into the front passenger seat of Chrysler, Ford and GM minivans.
www.braunlift.com/pages/consumer/chrysler.html

Child Resistant Seat Belt Buckle Guard™

Reduces the chance of unbuckling seat belt while vehicle is moving.
www.gadjits.com/Buckle%20guard.htm

Gait/Transfer Belt

Assists in safe transfer and ambulation while helping reduce caregiver back injuries.
www.posey.com
(click Products and then click Therapy Aids)



“HIDE & RIDE”: Interior Car, Truck or Van Lift

Lifts scooters into the trunk of a car, truck or minivan.

www.scooterone.com/scooter_lifts/Hide&Ride/hide_n_ride_lift.htm

800.229.1317

Invacare© “Rollite”™ Rollator

Lightweight design with a flip-up seat.

www.invacare.com

(Search Rollite Rollator)

Invacare© “Spyder”™ Wheelchair

Compact, lightweight wheelchair.

www.invacare.com

(Search Spyder Wheelchair)

The LiftVest™

Helps solve problems associated with transfers from a wheelchair to a car.

www.liftvest.com

800.300.5671

Mobility Seat™

This car seat replaces your vehicle's original seat with both a manual seat base and an upholstered seat that rotates and extends out the passenger or driver-side door to make entrance or exit easier.

www.braunlift.com/pages/consumer/mobilityseat.html

“Rise and Ride”

A full feature lift with a self-folding and unfolding platform.

www.scooterone.com/scooter_lifts/Rise%26Ride/rise_n_ride_lift.htm

Swivel Seat Cushion

Works as a “Lazy Susan,” making it easier to swing legs into car after sitting.

www.dynamic-living.com/swivel_cushion.htm



Resources for Caregivers

Helpful Products, Web Sites, Assistive Devices and Equipment

Tilt and Tote Wheelchair Carrier

The tilt-n-tote wheelchair carrier is designed to carry your standard folding wheelchair.
www.discount-wheelchair-ramps-wheelchair_scooter_carriers.htm
888.651.3431

Transport Chair

Lightweight, easily foldable travel wheelchair.
www.dynamic-living.com/transport_chair.htm

Helpful Web Sites

www.alz.org

The Alzheimer's Association's mission is to help. Their site is your gateway to a wealth of Alzheimer's related information.
800.272.3900

www.aoa.gov

U. S. Department of Health and Human Services, Administration on Aging's Web site. It is a great source for information on aging.
www.aoa.gov/caregivers/default.htm

www.blvd.com

Disability Resource Center: A Directory of Products and Services for the Elderly, Caregivers, Healthcare Professionals and People with Disabilities.

www.caregiving.com

Solutions to your caregiving situations throughout your caregiving years.

www.caregiving.org

National Alliance for Caregiving: A national resource for caregivers dedicated to providing support to family caregivers and the professionals who help them and to increasing public awareness of issues facing family caregiving.

www.discountramps.com

Large selection of ramps, carriers, and loading accessories for your truck, wheelchair, motorcycle, van, ATV, scooter, and tractor.

www.dlf.org.uk

Disabled Living Foundation: Solutions for Independent Living. As a national UK Charity, their vision is to provide a choice for people who use equipment to live a more independent life.

www.dynamic-living.com

Offers hundreds of kitchen products, bathroom helpers and unique daily living aids that promote a convenient, comfortable and safe home environment for people of all ages.

www.eldercare.gov

Eldercare Locator helps older adults and their caregivers find local services for seniors.
800.677.1116

www.easterseals.com

Visit this Web site to learn more about how Easter Seals helps children and adults with disabilities and their families.
800.221.6827

www.nfcacares.org

The National Family Caregivers Association (NFCA) is a grass roots organization created to educate, support, empower and speak up for the millions of Americans who care for chronically ill, aged or disabled loved ones.



Resources for Caregivers



www.nhtsa.dot.gov

Offers brochure "Adapting Motor Vehicles For People With Disabilities" and other important vehicle safety information.



www.nmeda.org

National Mobility Equipment Dealers Association, 900 East Skagway Avenue, Tampa, FL 33604
800.833.0427



www.projectaction.org

Funded through a cooperative agreement with the Federal Transit Administration, Easter Seals Project ACTION promotes cooperation between the transit industry and the disability community to increase mobility for people with disabilities under the ADA and beyond.
800.659.642 (voice) 202.347.7385 (TTY)



www.seniordrivers.org

AAA Foundation for Traffic Safety's senior driver web site for families, individuals and providers.

Sources for Assistive Devices and Adaptive Equipment



Assisted Living Store, Inc.

Products include kitchen tools, dressing aids, telephone amplifiers, bed rails, garden tools and more.
www.assistedlivingstore.com



Dynamic Living

Full range of products for activities of daily living and leisure.
www.dynamic-living.com

Hall's Medical Center: Auto Manufacturers' Mobility Programs

Details reimbursement for installing adaptive equipment for GM, Saturn, Ford, and Chrysler.

www.hallsmedicalcenter.com/bruno/brunoprod.php3?dep=1&sec1=1&prod=programs.txt

Independent Living Aids, Inc.

Products include clocks and watches, cooking aids, games and recreation aids, magnifiers and personal care items.

www.independentliving.com

800.537.2118

Independent Living Products

Full range of products for activities of daily living and leisure.

www.ilp-online.com

800.377.8033

Resources for Caregivers

A list of links to Web sites about caregiving resources and support.

www.makoa.org/caregiver.htm

Scooter Discounters

Electric scooters by scooter discounters offers electric scooters, scooter lifts, ramps, gentle lift recliners, batteries.

www.scooterone.com

Solutions for Better Aging: Shopping

A department store at your fingertips – clothing, personal care, nutrition, aids for daily living, mobility equipment and more to make you more comfortable, safer and healthier.

www.caregivers.com

Vehicle Ventures, Inc.: Mobility Products for People with Disabilities

815.874.5925

815.874.5911



References



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3 Community Transportation Association. *PASS: Passenger Service and Safety Certification*. Washington, D.C.: Community Transportation Association of America, 1996.

4 Ibid.

5 Hands of Grace. *Hands of Grace: Volunteer Training*. Delta, OH.



6 Szuch, Larry and Jodi Mount. *I CARE – Interfaith Companion and Ride Express – Volunteer Training Manual*. I CARE: Decatur, GA.

7 Paratransit Insurance Corporation. *Drivers Safety Course: Passenger Awareness – Student Text*. Gold Country Telecare, Inc.: Grass Valley, CA.



8 *Trading Places: Assisting Passengers with Special Needs*. Kansas RTAP Driver Training, September/October 2000

9 Ibid.



10 Paratransit Insurance Corporation. *Drivers Safety Course: Passenger Awareness – Student Text*. Gold Country Telecare, Inc.: Grass Valley, CA.

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- 11 *Trading Places: Assisting Passengers with Special Needs*. Kansas RTAP Driver Training, September/October 2000.
 - 12 West Austin Caregivers. *Volunteer Manual*. Austin, TX.
 - 13 Paratransit Insurance Corporation. *Drivers Safety Course: Passenger Awareness – Student Text*. Gold Country Telecare, Inc.: Grass Valley, CA.
 - 14 Ibid.
 - 15 “Validation: A Special Way of Caring.” *Ageless Design*. 02 July 2002. www.agelessdesign.com/nl9909-forthecaregiver.htm.
 - 16 Ibid.
 - 17 Ibid.
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Although the information and recommendations contained in this publication have been compiled from sources believed to be reliable, Easter Seals makes no guarantee as to, and assumes no responsibility for, the correctness, sufficiency or completeness of such information or recommendations. Other or additional safety measures may be required under particular circumstances.

Special Thanks To:

United States Department of Health and Human Services,

Administration on Aging

Alzheimer's Association

Federal Transit Administration

The National Council on the Aging

Faith in Action

AARP

Beverly Foundation

Community Transportation Association of America

National Highway Traffic Safety Administration

Easter Seals Project ACTION

National Association of Area Agencies on Aging

National Family Caregivers Association

National Association of State Units on Aging



Creating solutions, changing lives.

Easter Seals Project ACTION
ACHIEVING A COMMUNITY
TRANSFORMATION BY OUR ACTION

800.221.6827

800.659.6424