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CAREGIVER COACHES' CORNER

“LITTLE PLAYBOOK”

Livingwell Expo 2010
Caregivers Coaches Corner

CONTENTS

- You Need To Take Care of the Caregiver!!!
- How to Increase Circulation by Massaging the Legs
- Do Safe Transfers

Instructions for Caregivers

Sliding Board Transfers

Standing Pivot Transfer Without Assistance

Standing Pivot Transfer With Assistance

Special Transfers

Toilet

Bathtub

Car

Spotlight on Transfer Tips & Precautions

Body Mechanics for the Caregiver

Lifting

Pushing/Pulling

Dependent Transfers

Dependent Standing Pilot

Dependent Two-Person Life

Bed Positioning

Sidelying

Lying on the Back

Turning From the Back to Sidelying

- “Lifesaving” Ideas for Caregivers
- The New Health Care Law:
 What it Means for Family Caregivers
- Liability of Caregiving
- When is it Time To Stop Caregiving?

When is it Time to Stop Caregiving?

Care-giving is a very stressful situation. Stress either causes or exacerbates some 70 to 90 percent of all medical complaints, including tension and migraine headaches, high blood pressure, asthma, nervous stomach, bowel problems, and chronic lower back pains. There is research evidence indicating stress plays a role in a person's susceptibility to heart disease, stroke, and cancer.

Stress has also been implicated in psychological disorders such as anxiety reactions, depressions and phobias, as well as poor work performance, drug and alcohol abuse, insomnia, and unexplained violence.

If you are experiencing any of the above, it is extremely important that you learn and use various techniques for stress reduction (some are mentioned in this booklet), come to the decision, both for your well-being and that of your care-receiver that it is time to stop caregiving.

Below are some telltale signs which can help you assess when you have reached this fork in the road; seek help professional help, utilize more stress reduction methods, or stop care-giving:

- snapping at the care-receiver constantly even over little things,
- being constantly irritated,
- seldom laughing anymore,
- feeling constantly tired or pressured,
- losing sleep, failing to fall asleep for hours, sleeping restlessly all night long,
- yelling or screaming, or having crying fits, or rages frequently,
- withholding affection, feelings of goodwill from the care-recipient,
- withholding food, baths, dressing changes, etc.,
- constantly blaming the care-receiver for your being in this situation (his/her isolated caregiver),
- refusing to go out anymore, even for a walk because **he/she needs me**,
- withholding expenditures for goods or services he/she needs because he/she is going to die soon and it is wasted money,

While these are not exclusive, they indicate a classic picture of **caregiver burn-out**. The treatment for caregiver burnout is simple -- get help and get away for extended periods, either through stress management respite help or through a complete change in care-giving.

No one can remain a full-time caregiver forever; the job is much too strenuous and stressful. The point we wish to set forth is: **When should I say this is my limit; I am not able to do any more.** Be honest with yourself, and when **that limit** has been reached, STOP! Research alternatives, request help from qualified professionals, and rest easy, because you did the right thing!

Liability of Caregiving

Anyone who accepts the responsibilities of a caregiver must also understand that there are a number of legal duties or liabilities that come with it.

Many states including California have passed elderly abuse laws. Caregivers are bound by these laws in two ways: not to abuse the elder person (physically, mentally or monetarily) and report any incidents of abuse or suspected abuse.

As a caregiver, you must provide a clean and safe environment, nutritious meals, clean bedding, and clothes. At the same time, if you are in charge of the elderly person's finances, you must use that money properly, purchasing necessary services for the benefit of the person to whom care is given. Failure to provide care, failure to get care, and failure to purchase care are all forms of abuse or neglect.

In addition, caregivers may not physically, sexually or psychologically abuse the person receiving the care. Yelling, screaming, withholding affection, etc., are as much an abuse of the person as is striking the person with the hand or with objects.

Therefore, if you are contemplating becoming, or are now a caregiver, you must be ready to accept the physical, psychological and legal duties to provide the necessary care.

If you are reaching a point where you are no longer able, physically or emotionally, to provide the proper care, we urge you to consider the alternatives to personal care-giving and to seek help.



You Need To Take Care of the Caregiver!!!

It's easy to forget about your own needs when you are a caregiver. But doing that takes a toll on your health. Here are some caregiver support tips to help you stay healthy and reduce your stress while you're caring for someone else.

Accept your own limits.

As a caregiver, you don't have to do it all, and you shouldn't try. Accept that there are limits to what you can do as a caregiver. Admit when you feel overwhelmed, and ask for help.

Create a caregiver support team.

Before you can ask for help, you need to know who you can ask. Plan ahead for times when you'll need help by making a list of people who are willing to help you with caregiver support.

Family members, friends and professional respite care workers can give you a break or help out when you can't be there. Include their phone numbers on your list, along with the times they are available and the tasks they're willing (or unwilling) to perform. Always keep a copy of the list with you; you never know when you may need to ask someone for help.

Get organized.

Being a caregiver can be a full-time job, even if you already *have* a full-time job. Make a realistic schedule with your family and friends to make sure you get the caregiver support you need; assign chores, and make sure everyone knows what to do and when to do it. This will help everyone stay organized, and it will help you, as primary caregiver, to manage the extra demands on your time.

Schedule time for yourself.

Don't forget to schedule time for activities you enjoy. There are more important things than doing the laundry, and caregiver support is one of them. Remember, this is about staying healthy in mind and body. You need to make time to have fun now and then.

Make your own health your first priority.

This may sound selfish, but it's not. Being a caregiver is a big job, and the only way you can provide the caregiving your loved one needs is to **make sure you stay healthy**.

The kind of stress you're trying to manage every day can easily lead to depression; staying fit and healthy can help you cope, reduce stress, and make it easier to get through tough days when they come.

Following these tips for caregiver support will help you stay on the right track:

- **Eat a balanced diet.** This is vital to good long-term health, and it shouldn't be hard to manage. Chances are the person you're caring for has been ordered to eat well, and you're probably preparing and/or sharing many of those meals.
- **Get plenty of rest.** Try to get the requisite eight hours every night. If you're short on sleep because your caregiver duties require you to be up and down during the night, take naps the following day when your loved one is sleeping.

Exercise regularly.

Aim for 30-60 minutes of exercise four to six times a week; even a walk around the block will help clear your mind and keep you more fit. Regular exercise will give you more energy, reduce your stress, and elevate your mood. If you can work in some strength training twice a week, that will help keep your bones firm and your muscles strong, both essential if you have to help lift and support the person in your care.

- **Relax.** Do relaxation exercises--such as deep breathing or meditating--to reduce caregiver stress. If possible, set aside a few minutes at the beginning and end of your day to practice these techniques.
Consciously relaxing in this way will help you enter the day more calmly, and make it easier for you to sleep at night. You can also do deep breathing now and then throughout the day to help keep your stress under control.
- **Take a break.** At least once or twice each week, stop being a caregiver for awhile and take some time for yourself. If you do, you'll be happier and better able to care for your loved one.

See your doctor.

Get regular medical check-ups; you need them more than ever now, because you're managing a lot of extra stress and emotional turmoil.



Being a caregiver for someone you love is one of the toughest jobs imaginable. It's frustrating and terrifying, exhausting and overwhelming, but it can be one of the most rewarding things you'll ever do — a supreme act of love.

But don't forget caregiver support: in order to provide the best care for your loved one, you have to take care of yourself.

HEALTH CARE *and you*



- The Medicaid program will help more people have health insurance. In 2014 Medicaid will expand to children, parents, and adults without children who do not have Medicare and who have a limited income. Currently, to qualify for Medicaid you must have an income under about \$14,400 if you are single or under \$20,000 for a couple.
- Starting 2014, you may be able to get tax credits to help pay for health insurance purchased through a health insurance exchange. You will qualify if you earn less than \$58,280 for a couple or \$43,320 as an individual.

Improves insurance practices

- As of 2010, insurance companies can't drop your health coverage if you become sick. Your health insurance is guaranteed as long as you pay your premiums.
- Insurance companies can no longer place lifetime or restrictive annual limits on your health coverage. This change will ensure that your benefits won't run out when you need them the most. The ban on lifetime limits begins in 2010, while the ban on annual limits begins in 2014.
- Starting in 2014, you or the person you care for cannot be denied health insurance because of a pre-existing condition.

Expands access to long-term care services and information

- Starting in 2011, you can get more information about nursing home inspections, complaints against facilities, and resident rights. This information will help you make decisions

if you need to select a nursing home for the person you care for.

- States can receive more money to expand home and community-based services. For example, under the Community First Choice Option, states choosing to participate will get more federal dollars to provide certain home- and community-based services to people with disabilities who live at home but need long-term services and supports. These changes also begin in 2011.

- If you are working, you can get long-term care insurance. This new voluntary insurance will provide a cash benefit to help you pay for some of your future long-term services and supports. You will be able to get the cash benefit after you have paid the premiums for at least five years, have worked at least three of those initial five years and have met other requirements. If your employer participates in the program, you will be enrolled automatically unless you choose not to participate. You will also be able to buy this insurance if your employer doesn't participate, if you have more than one employer or if you are self-employed. This program should start in 2012 or 2013.

Check www.aarp.org/getthefacts frequently for the latest information.

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The New Health Care Law: What it Means for Family Caregivers

If you are a family caregiver, the new health care law may benefit you and the person you care for in several ways. The law makes it easier to get health coverage, helps make it more affordable, improves insurance practices, and expands access to long-term care services and information.

Some of these changes start this year. Others will phase in over the next several years. By knowing what's in the law many of these changes can help you with your own care and as a family caregiver for your relative or friend.

Makes it easier to get health insurance

- If you or the person you care for have been uninsured for six months and have a pre-existing condition, you may be able to get temporary health insurance coverage. This coverage – called the Pre-existing Condition Insurance Plan (PCIP) – is a first step to help people with pre-existing health conditions get the coverage they need. Applications for this temporary insurance program started on July 1, 2010 and will continue until January 1, 2014. Beginning in 2014, health insurance will then be available through a new health insurance exchange in your state. You'll find more information about how to apply for PCIP at www.healthcare.gov.

- The new law creates health insurance exchanges for people who don't have coverage through their job. Exchanges will provide "one stop shopping" so it will be easier for you to compare plans and prices for yourself and the person you care for. Anyone who is eligible for insurance through an exchange but does not purchase it will be subject to a penalty. Health insurance exchanges will start offering insurance in 2014.

- All plans offered through the health insurance exchanges must include medical and mental health care benefits, prescription drugs, and rehabilitation services. You will be able to pick among four levels of coverage to fit your needs or the needs of the person you care for.

Helps make health coverage more affordable

- Starting in 2010, if you have a new health insurance plan you will not have to pay some of the costs for preventive care. This may include services such as mammograms, immunizations, and screenings for diabetes and many cancers.

How to Increase Circulation by Massaging the Legs

We all know how important it is to have and maintain good circulation in our bodies, no matter who you are.

Here is a step-by-step way to give a leg massage to improve and help maintain proper circulation in your legs. Give these massages to yourself or to someone else as a relaxing treat.



Step 1. To start, wet some towels with hot water (but not so hot it will burn the skin). Now, wrap the towels around bare legs and feet if you wish. Let the towels set until they cool.

Step 2. Remove the towels and rub your choice of lotion on the leg and work with one leg at a time. Start at the ankle and rotate with your fingers in a circular motion using both hands so you are rotating all the way around the leg. Continue these rotations working all the way around like a spiral up to the knee.

Step 3. Starting back at the ankle, place your palms on each side of the leg. Using your thumb, firmly press down and push in a straight line all the way up to the knee. You will feel the bone in between your thumbs on the way up. Now go back down to the ankle, spread your thumbs a little farther apart and repeat the pressured straight line up to the knee. If you are able to reach around and do this to the back of the leg, repeat the pressured line.

Step 4. Firmly hold the ankle with one hand and place the other hand with the four fingers (not the thumb) on the calf muscle. Begin rotating deep, circular motions into the calf. Continue as long as desired.

Step 5. The last manipulation you want to do is to firmly grasp the ankle using the index finger and thumb of both hands. Don't just use your finger-tips, grasp firmly enough into the curve between your index finger and thumb. Now, twist back and forth, wrists together, then apart...together, apart...and so on. Do this manipulation all the way up to the knee. Repeat this a few more times.

Repeat steps 1-5 for the other leg.

To finish up, run the hot water over the towels again and place them around the legs just as before. Let them cool and use them to wipe off the lotion as you slide them off the legs. Massaging the leg from ankle to leg improves the circulation by manipulation with the blood flow. *This is also excellent to do for people with limited mobility.*

I hope you enjoy this relaxing massage whether you're giving it to yourself or it's being given to you...enjoy!

Caution:

Massaging your legs can stimulate circulation; however, if you have pain or redness in your calf, never massage your leg. Pain or redness in your calf can signify a blood clot, and by massaging it, you may dislodge it. Dislodging a blood clot can be life-threatening, as it can travel to the heart and lungs.

Do Safe Transfers

MOVING WITH HELP

Transfer techniques should be taught to primary caregivers.

Keep in mind that all transfers take some practice. With experience, caregivers will be able to do them with ease.

SPECIAL NOTE: Caregivers: The following descriptions are general guidelines. Review them with your health care team to be sure they apply to the person you're caring for. Transfer needs can vary among individuals, and for safety's sake you should let a PT or OT show you how to transfer your loved one.



INSTRUCTIONS FOR CAREGIVERS

Sliding Board Transfer

The sliding board transfer requires the use of a transfer belt or gait belt and a sliding board or transfer board. Use the sliding transfer when moving a person to or from a bed or chair into the wheelchair.



Position the wheelchair and lock it parallel to or at a slight angle to the bed.

When you're transferring a person from the bed to the wheelchair, you should remove the armrest on the side you're transferring to. He should lean slightly and you should place the sliding board well under the buttocks, with the other end of the board over the wheelchair seat. Be careful not to pinch him between the board and the bed.

Stand in front of your loved one to block his knees. Grasp his transfer belt at the back and perform the transfer by a series of leaning and sliding movements until he's moved down the board into the chair.

When he's on the chair, remove the board and release him when he's sitting in a position he can maintain.

You can reverse this procedure when transferring him to a bed.

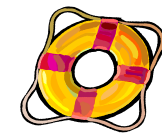
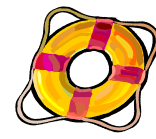
Standing Pivot Transfer Without Assistance

Here's a way of transferring someone from the wheelchair to the bed without a sliding board.

The loved one moves to the edge of the locked wheelchair and, using the arms of the chair, pushes to a standing position.

He or she pivots by moving the feet in small increments, and then reaches for the bed. Note: Reaching for the bed before pivoting may lead to a loss of balance.

The person sits by lowering himself to the bed.



"Lifesaving" Ideas For Caregivers

Listen to the falling rain

Read inspiring books

Breathe in deeply and exhale slowly

Enjoy a comedy at your favorite theatre

Take a stroll in the park

Phone old friends

Reflect on good memories

Work on a hobby

Write letters to close friends

Take a bubble bath

Blow bubbles

Listen to your favorite music

Watch the sunset

Always look for the silver lining

Take off your watch

Sip a cup of hot chocolate or tea

Read the comics

Simplify your life

Take a nap

Soak your feet in hot water

Enjoy a nature walk

Paint a picture

Buy yourself a present

Look at your favorite photos

Sing in the shower

Make popcorn

Watch a favorite TV show

Play a board game with friends

Relax in a rocking chair

List the things that make you smile

Laugh out loud



BED POSITIONING

If your loved one is unable to move independently in bed, a bed-positioning program will promote his or her comfort and reduce the risk of skin breakdown.

SPECIAL NOTE: The skin over bony areas is the most susceptible to problems from pressure caused by staying in one position in a bed or wheelchair for many hours. The length of time that a person can tolerate pressure varies. Should skin breakdown occur, it's important to contact your physician for proper wound management.

Bed positioning will also help to minimize the swelling associated with severe weakness. This swelling or accumulation of fluid under the skin, known as edema, occurs as a result of muscle inactivity and the effects of gravity on the limbs. It occurs most frequently in the hands and feet. Proper elevation of the limbs helps to reduce the swelling and encourages blood flow.

Bed positioning should:

- be comfortable for the loved one
- be changed frequently
- keep the person's head in line with his body, neither too flexed nor too extended
- prevent friction or compression between body parts by the use of pillows or other position devices

There are two basic positions for lying in a standard bed — on the back and sidelying. The position should be changed at least every two hours from lying on the right side, to lying on the back, and then to lying on the left side.

If a hospital bed is available, the positioning options increase owing to the flexibility of the bed. If you notice a reddened area that lasts longer than 20 minutes, you should increase the frequency of the turning schedule.

This need varies greatly from one individual to another. Consult with your PT, OT or nurse for specific instructions in bed positioning.

Sidelying

Place a pillow between the knees of the person in bed and wedge another pillow behind the back. Elevate the upper arm on a pillow.

Lying on the Back

Place a pillow under the knees and elevate both arms slightly with pillows.

Turning From the Back to Sidelying

Stand on the side of the bed that the person is to be rolled toward (i.e., if rolling him to the right side, stand on the right side of the bed). Face the bed squarely and grasp the end of the [draw sheet](#) farthest from you at shoulder and hip level. Keep your back straight and knees bent.

Lean back and pull the draw sheet to roll the person onto his or her side. Stabilize him at the shoulder with one hand while wedging a pillow behind his back with the other hand.

Bend his knees slightly forward and place a pillow between his legs. Position his head in proper alignment with the body. Elevate his upper arm on a pillow and place the call button within his reach.

To reposition the person on his back, reverse the technique.

Standing Pivot Transfer With Assistance



Your loved one should assist as much as possible when being helped to the standing position. In this way you don't actually lift, but only help them into the upright position. This requires the use of good body mechanics and a transfer belt.

Remove the footrests from the wheelchair; then the person being transferred places his feet on the floor directly under the knees. He slides forward to the edge of the locked wheelchair.

Place your feet and knees to the outside of his feet and knees. He then places his hands on the armrests in preparation to assist in pushing to the standing position.

With your knees bent, grasp the person's transfer belt at the back and initiate a forward rocking motion.

Give the command to "stand" and straighten your knees to assist him to a standing position. Continue to grasp the transfer belt as they pivot toward the bed. A transfer pivot disc is often helpful in this process.

They lower them self to the bed, but don't release them until they are in a position they can maintain.

SPECIAL TRANSFERS

When transferring your loved one to the toilet, car or bathtub, you should use the same techniques described above, with the following additional considerations:

Toilet

Position the locked wheelchair facing the toilet at a slight angle. After the person has achieved standing, assist him in partially disrobing. Then help him to sit on the toilet.

Bathtub

Position the locked wheelchair parallel to the tub and remove the footrests and the armrest nearest the tub. The person moves to the outside edge of the tub bench while you assist in maintaining his balance.

Place one arm around his shoulders and the other arm under the knees. With one movement, pivot him to face forward on the bench while swinging the legs into the tub.

Car

Position the locked wheelchair parallel to the car. Transfer your loved one to the outside edge of the car seat.

Place one arm around his shoulders and the other arm under the knees. With one movement, pivot his legs onto the floorboard of the car.

Spotlight on Transfer Tips and Precautions

- To prevent back injury to you (the caregiver), bend at the hips and knees, not at the waist, as you prepare to lift someone; then straighten at the hips and knees as you lift.
- Keep a wide base of support by spreading your feet apart. If you're transferring someone from one place to another, stagger your feet in a walking position, and shift your weight from front to back as you lift, while keeping the person as close to you as possible.
- To avoid back injury: When turning, pivot on your feet or move them. Don't twist at the waist. For added back support, consider wearing a safety belt like those used by workers who frequently lift and carry items on the job.
- Wear shoes with low heels, flexible nonslip soles and closed backs.
- Plan ahead. Know where you're going and how you're going to get there, and make sure the person you're lifting also knows. Move everything out of the way, and make sure the brakes are engaged on any wheeled devices. Transfer him to even, stable surfaces; avoid low or overstuffed chairs and couches.
- If he starts to fall, ease him down onto the nearest surface — a chair, bed or even the floor. Don't stretch to complete the intended transfer. You're likely to lose your balance, strain your muscles, and injure both yourself and the person you're transferring.
- Tailor your lifting and transferring techniques to the type and degree of weakness in the person with ALS. Needs may change over time as weakness progresses.
- Use mechanical devices to help you whenever possible.
- If the person you're transferring is using a wheelchair, be sure to stabilize it by securing the brakes. Remove the footrests and armrest on the side he's being transferred toward.
- Don't be discouraged if a lift seems cumbersome or too difficult to use at first. Practice makes perfect!

BODY MECHANICS FOR THE CAREGIVER



As you assume more responsibility for the care of your loved one, your risk of injury increases. The use of proper body mechanics will minimize this risk. Good body mechanics distributes the stress over several sets of muscles and uses the stronger muscles. General principles are as follows:

Lifting

Face the person squarely, with your feet shoulder width apart.

Position yourself as close to him or her as possible. Bend your knees and lift with the legs rather than the back. Keep your head up.

Pushing/Pulling

Keep your feet apart — one foot in front of the other. Shift your weight from your back foot to your front foot. It's usually safer to push than to pull.



DEPENDENT TRANSFERS

If the person is unable to assist in the transfer, a dependent transfer will be necessary. There are two major types of dependent transfers: dependent standing pivot and a two-person lift. You may also choose to use a [mechanical or hydraulic lift](#). A physical therapist will assist you in selecting the proper type of transfer and instruct you in how to do it.

Dependent Standing Pivot

When transferring someone from a wheelchair to a bed, place the locked wheelchair parallel to the bed and remove both footrests and the armrest nearest the bed. With the person's feet on the floor, move him to the edge of the seat by grasping under the knees and pulling forward. Place his feet outside your feet and block his knees.

Reach around the back of the person and grasp the transfer belt while he attempts to hold his arms together in front of the body.

Initiate a rocking motion and then straighten his legs to lift him out of the chair. The lift need be only high enough to clear the wheelchair.

In a swift motion, pivot toward the bed, rotating the person to the proper position for sitting. Lower him to the bed but don't release him until he's in a position that can be maintained.

Dependent Two-Person Lift

Position the wheelchair at a slight angle to the bed. Remove both footrests and the armrest nearest the bed. Caregiver #1 (generally the stronger person) should stand next to under the knees. On command from caregiver #1, raise the person to a height that will ensure that he clears all parts of the wheelchair. In one smooth motion caregiver #1 should step to the side and lower him onto the bed.