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Family Caregiver Resources

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Living with Parkinson's Disease

Parkinson's is a condition that goes on for many years, even decades. Family members become intimately involved with their loved one's needs and changing abilities. From eating to walking to talking, the nerve and muscle impact of Parkinson's is felt in all aspects of daily life. Fortunately, there are things you can do to improve quality of life for all of you. Check out the tips on this handout.

Dietary tips to ease common problems



Dietary habits make a big difference in quality of life for people with Parkinson's. Eating-related symptoms often crop up. For example, difficulties with swallowing. Also, problems with constipation as a result of slow muscle response. And problematic food-drug interactions. On the plus side, some foods can reduce the free radicals common in Parkinson's.

Here are some tips to discuss with your loved one.

- In the morning, a glass of warm fluids such as hot water, tea, or warmed prune juice helps kick-start the bowels. A high-fiber diet and six 8 oz. glasses of fluid per day is a natural remedy. High-fiber foods include vegetables, legumes, and whole grains. Also fruits with the peel left on. There are prescription medicines that can help. And certainly, exercise helps all aspects of Parkinson's.
- **Swallowing problems.** Coughing or choking can be relieved by sitting upright at a 90° angle while eating and "tucking the chin" down toward the neck when swallowing. Also try drinking from a wide-rim glass or cup. Taking smaller bites and chewing thoroughly can help. (Plan for longer meal times. Also, smaller, more-frequent meals.) Talk with a speech therapist or dietitian about other solutions.
- **Medication-related issues.** Certain Parkinson's drugs work best when taken in the absence of protein-rich foods. Ideally, about one hour before or two hours after meals. This timing can be challenging. Other Parkinson's drugs may conflict with certain foods and minerals or cause dehydration. Consult with your loved one's doctor and ask for a session with a dietitian or nurse to create a plan.
- Your relative with Parkinson's has more free radicals than their same-age peers do. Antioxidant foods help mop up these toxic elements. The best fruits are deeply colored: Blueberries, strawberries, raspberries, and red or purple grapes. Best veggies, also deeply colored, include red cabbage, spinach, kale, and sweet potatoes.



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Fighting Parkinson's with exercise



If your loved one has Parkinson's disease, you have likely observed physical symptoms such as tremors, slowed movement, and poor balance. In addition to treatment with medication, evidence is mounting that exercise itself can reduce or delay progression of these symptoms. Even as little as 2.5 hours of physical activity a week.

Benefits and types of exercise. The benefits of exercise include smoother and quicker movements and improved balance and coordination. Plus, exercise can ease depression, which is common in Parkinson's. Exercise is not a *cure* for Parkinson's. But overall, your relative will feel and move better.

There is no one "best" exercise for Parkinson's. The goal is to get going on some kind of activity and keep going over the long term.

Have your relative talk with their doctor and get a referral to a physical therapist specializing in Parkinson's. The therapist can suggest exercises best suited to your loved one's likes and needs, such as

- **boxing.** Punching a bag reinforces confidence and fast, coordinated movements. No hitting of others!
- **dance.** This movement blends creativity with agility.
- **rowing or tandem cycling.** Doing it with others can help ensure a pace that builds stamina. A stationary bike with a forced pace may work as well.
- **tai chi, qi gong, or yoga.** These activities support better balance.

Reach a bit, push a bit

Your loved one may prefer to start with something more familiar, such as walking or swimming. The key is to get moving! With Parkinson's, movements gradually become more restricted. Research indicates that a "forced-pace" activity that feels to the person a little harder than they can do is more likely to extend ease of motion.

Communication challenges

If the person you care for has Parkinson's, you may be surprised to discover the many ways the disease hampers communication. Voice problems alone affect 60%–80% of people with this condition. Low volume and slurred speech may make it hard at times for you to grasp what your loved one is saying. They may be slow to respond. Or words may tumble out very quickly and somewhat jumbled. Misunderstandings and frustration are common. Fortunately, both of you can take steps to help offset communication issues.

Facial masking. The face has 43 muscles. Their movement gives us expression. But Parkinson's restricts facial muscles just as it restricts leg and arm muscles. The result is a stiff or "blank" expression. Typically, such a look indicates anger, boredom, or sadness. But with Parkinson's, none of that may be true. Ask your relative what they are feeling about the topic you are discussing. It may be far from what their nonverbal cues are "telling" you.

To minimize problems:

- Aim for one-on-one conversations or small groups
- Choose a quiet room with few distractions and sit near each other
- Encourage your loved one to take a deep breath before speaking
- Listen patiently. Pressure to perform will make speech more difficult

Try speech therapy and singing. A speech therapist with special Parkinson's training can provide facial and voice exercises. Ask in particular about an LSVT "Loud" program. Named for the Parkinson's patient it was designed for, Lee Silverman Voice Treatment helps people recalibrate their impression of what "loud enough" is. The speech therapist may recommend helpful devices such as a portable voice amplifier or singing as a fun way to practice breath control. Singing in a group also provides an opportunity for socializing, accomplishment, and fun!

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A physical therapist can design and monitor a program that strikes a balance between a pace that is too much and one that is too little.
