

Community Resources and Practical Pointers for Parkinson's Disease

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Due to time constraints, it is difficult for physicians and their office staff to know all of the various resources available for the many complex issues that may arise for the individual with Parkinson's disease. There are numerous national and local organizations available to assist the patient and family. A list of Parkinson's disease organizations and other useful resources is listed at the end of the article.



Ms. Pressler has more than 25 years experience working with neurological disease and the past 8 years of working specifically with Parkinson's disease at CNI's Movement Disorders Center. As a nurse educator, Josette provides inservices to many healthcare providers including nursing personnel at hospitals, extended care facilities, assisted living facilities and also provides education to many different community groups. Josette is a member of the Parkinson Association of the Rockies (PAR) education team which provides information to Parkinson support groups in Colorado, Wyoming, and western Nebraska.

Introduction. Parkinson's disease (PD) is a progressive neurodegenerative disease and at this time, there is no cure, however, it is one of the few neurological disorders whose symptoms can be medically managed for many years with proper medications. Disease progression and severity varies greatly between individuals. As the disease progresses, many aspects of the patient's and their families lives may be affected. Rigidity, bradykinesia, tremor, and balance issues are not the only difficulties that a patient may have. There are numerous non-motor symptoms that may affect ones independence. Due to the wide range of challenges that one may face, accessibility to many different types of resources may be needed. This article intends to provide a general cross-section of resources available for the individual with PD and to provide a few practical pointers that may ease some daily tasks. By no means does this article contain all resources available.

PD Education and Social Support. It is always important with any illness to educate yourself and family members. For Parkinson's disease, there are many educational resources available both nationally and locally. Locally, CNI's

Movement Disorders Center has neurologists, nurse practitioners, and nurses that are specifically trained in Parkinson's disease. The Center has numerous research studies that encompass all stages of disease. Support groups prove to be quite beneficial for many individuals; we are fortunate in Colorado to have Parkinson's Association of the Rockies (PAR) which not only has a wonderful PD library, but has over 30 PD support groups in Colorado, western Nebraska, and Wyoming. Such support groups allow patients and families to network with others who have the same disease and to share coping strategies with the physical, social, and psychological challenges that are faced on a daily basis.

Mobility and Safety. As the disease progresses, a shuffling quality of gait, decreased balance and freezing episodes may interfere with ambulation. A single point cane or a walker with 4 wheels or casters may be helpful. Basic aluminum walkers and 4-pronged canes are not appropriate for the individual with PD. To avoid falls from tripping, it is recommended that scatter rugs be removed from the home. To decrease freezing episodes, rooms should not be cluttered or crowded. For people with PD

that have difficulty standing from a chair, it is helpful to have couches and chairs at a level where it is easier to stand, preferably with armrests to push up from. There are “lift chairs” which have proven to be quite helpful for the patient with PD who has difficulty arising from a chair.

Personal Hygiene/Grooming.

Regarding safety with bathing and toileting, install handrails in the shower and toilet areas. A shower bench or tub/transfer bench may be quite helpful as is a hand held shower head. Please remember to put non-skid rubber mats in the bottom of showers. If mobility is a problem, particularly at night when one awakens and has the need to use the bathroom, make sure the area to the bathroom is well lit or use a urinal or bedside commode. Rigidity, decreased dexterity and tremor may make it difficult to handle toothbrushes, razors etc. Electric razors and electric toothbrushes help the individual to remain independent with these daily tasks.

Home Evaluations. It may be helpful to have a home evaluation by a physical therapist or occupational therapist to maximize safety and independence. They can give helpful suggestions and recommend the appropriate adaptive equipment for the patient and family. They may also be able to let the doctor know if the patient can no longer stay safely in the home.

Feeding/Eating. For the advanced PD patient, it is better to eat meals during the “on” times. Food may need to be cut into smaller bite-size pieces which will be easier to chew and swallow. Alternating liquids and solids can help with swallowing. If the patient chokes on thin liquids, then a

thickening agent may be requested. If the patient experiences frequent coughing or choking while eating, consider a swallow evaluation by a speech-language pathologist.

Dressing. Due to decreased balance, it is safer to sit down while dressing. It may be helpful to use a footstool to put on socks and shoes. Clothing with Velcro closures and elastic waistbands for pants and skirts make dressing easier. There are now many different types of shoes with Velcro fasteners instead of laces or there are “curly fries” elastic-type shoelaces available.

Sleep Environment. Bed mobility may be significantly impaired due to medications wearing off at night. For easier bed mobility, satin sheets or pajamas can help. Avoid flannel sheets and heavy comforters, as they may impair mobility further. Keep items off the bedroom floor to avoid tripping. Some patients benefit from a rope around the headboard for leverage or a floor to ceiling pole next to the head of the bed. Many patients with PD who have severe mobility problems resort to a recliner for sleeping.

Communication/Speech. The most common speech problem associated with PD is lowered volume of speech. It may be difficult to hear the person with PD, however, many times the PD person thinks they are talking at a normal volume. The Lee Silverman Voice Therapy (LSVT) that is used successfully for Parkinson’s disease voice improvement internationally was developed at the National Center for Voice and Speech right here in Denver.

Driving. The issue of driving should be addressed, particularly with the individual who has motor fluctuations.

Reaction times may be diminished, especially when the patient is “off”, making driving more dangerous. Patients with PD also may have problems with task shifting so it is recommended that they drive with minimal distractions in well lit, low traffic situations. Driving evaluations are recommended if there is any question about ones ability to remain safe on the road.

Medications and Affordability. People with PD are usually on multiple medications for symptomatic control. These medications are quite costly and, if one does not have an insurance medication plan, may be prohibitive to obtain. If the patient does not have a medication plan and if purchasing the medications out of pocket is a financial hardship, most pharmaceutical companies have patient assistance programs that upon qualification, provide the drugs free of charge. If the patient is a US Veteran, by all means, have them contact their local VA. If the patient is experiencing financial difficulties, it may be appropriate to have them contact their County of residence, Human/Social Services department to see if they would qualify for any programs.

Caregivers. Caregiving 24/7 is extremely difficult. Access the caregiver for “burn out” or depression during your patients interview. Have the caregiver call in “the troops”, whether it is a family member, friend, or local senior organization, have them get some respite!! Sometimes just a few hours a week may help keep the patient at home. Other families may need a few days which many extended care facilities can provide. Touring the facility first is recommended. Today, there are many adult day-care facilities that have different programs for different levels of care.

Encourage continued activities that they find enjoyable. Encourage rest, regular exercise and a healthy diet.

Conclusion. Due to the numerous challenges that the patient and family may face as Parkinson’s disease advances, accessibility to many different organizations may be needed and/or helpful. We are fortunate in the state of Colorado to have access to many of these organizations both locally and nationally. Many of the listed organizations provide reading materials and handouts free of charge. If you are a physician, please do not hesitate to have your patients contact the various organizations.

Address questions and comments to:

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National Parkinson Foundation
Center of Excellence Coordinator
701 E. Hampden Avenue, #330
Englewood, CO 80113

Parkinson's Disease Resource List

The following is a list of resources available, as mentioned earlier in this article, this by no means is a list of all resources but a general cross-section.

Parkinson's organizations:

Colorado Neurological Institute

Movement Disorders Center

701 E. Hampden Ave., Suite 530

Englewood, CO 80113

www.thecni.org

National Parkinson Foundation

1501 NW 9th Ave/Bob Hope Road

Miami, FL 33136-1494

1 (800) 327-4545

www.parkinson.org

Parkinson Association of the Rockies

1420 Ogden St.

Denver, CO 80218

(303) 830-1839

www.parkinsonrockies.org

Colorado Parkinson Foundation

Colorado Springs, CO

Ric Pfarrer

(719) 495-1853

Parkinson's Disease Foundation

710 West 168th St.

NY, NY 10032-9982

1 (800) 457-6676

www.PDF.org

American Parkinson Disease Association

1250 Hylan Blvd. #48

Staten Island, NY 10305

1 (800) 223-2732

www.APDAParkinson.org

Michael J. Fox Foundation

Grand Central Station

PO Box 4777

NY, NY 10163

1 (800) 708-7644

www.michaeljfox.org

Worldwide Education & Awareness for

Movement Disorders

www.wemove.org

Parkinson's disease advocacy:

Parkinson's Action Network

1000 Vermont Ave. NW # 900

Washington DC 20005

1 (800) 850-4726

www.parkinsonaction.org

Patient Advocate Foundation

www.patientadvocate.org

Financial Assistance-Human Services:

Contact your county of residence:

Adams County (303) 287-8831

Arapahoe County (303) 636-1130

Boulder County (303) 441-1000

Broomfield County (720) 887-2200

Denver County (720) 944-3666

Douglas County (303) 688-4825

Jefferson County (303) 271-1388

Adaptive Driving Programs:

"Behind the Wheel"

Spalding Rehabilitation Hospital

900 Potomac St.

Aurora, CO 80011

(303) 363-5321

www.SpaldingRehab.com

Master Drive of Colorado Springs

3280 E. Woodmen Rd.

Colorado Springs, CO 80920

(719) 260-0999

www.masterdrive.com

Master Drive of Denver, Inc.
15659 E. Hinsdale Dr.
Englewood, CO 80112
(303) 627-4447
www.masterdrive.com
Master Drive of Ft. Collins and Loveland
5609 Goldco Dr.
Loveland, CO 80538
(970) 593-6362
www.masterdrive.com

Speech Therapy:

National Center for Voice and Speech
DCPA Administration Building
1245 Champa St.
Denver, CO 80204
(303) 893-4000
www.lsvt.org

*Physical therapy, Occupational therapy,
Speech therapy:*

Most local hospitals have outpatient departments, or there may be free-standing therapy centers in your community.

Adaptive Equipment:

You Can Too Can
2223 S. Monaco Pkwy
Denver, CO 80222
(303) 759-9525
www.youcantoocan.com

Pathways Homecare Center
11091 E. Mississippi Ave.
Aurora, CO 80012
(720) 207-9540
www.pathwayshomecare.org

AAA Medical
2095 W. Hampden Ave.
Englewood, CO 80110
(303) 781-1474
www.AAAmedical.com

The following is a wonderful organization that publishes a free booklet loaded with information for where to contact or go for many different services available:

Seniors Resource Guide
(303) 642-2232
www.SeniorsResourceGuide.com