

UC Neuroscience Institute
AT UNIVERSITY HOSPITAL

GARDNER CENTER FOR
PARKINSON'S DISEASE
& MOVEMENT DISORDERS

UNIVERSITY OF
Cincinnati

Navigating Disability and Insurance

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Key Points

- Be prepared
- Be informed
- Be responsible

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Understanding Your Rights

- Legal rights
- ADA act
- Income replacement policies
- Social Security
- Long-term insurance

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Legal Rights

- Right to be free from discrimination on the basis of disability
- Right to participate in disability-based benefits programs

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Important Questions

- What are all of your rights from those sources?
- When do they become rights?
- How do you exercise such rights?
- How do they fit together?
- How can you maximize the bundle of rights to help ease the difficulty of managing a diagnosis of Parkinson's disease?

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Americans with Disabilities Act

“no covered entity (employers employing more than 15 employees) shall discriminate against a qualified individual on the basis of disability in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment”

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“not making reasonable accommodations to the known physical or mental limitations of an otherwise qualified individual with a disability who is an applicant or employee, unless such covered entity can demonstrate that the accommodation would impose an undue hardship on the operation of the business of such covered entity”

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Income Replacement Policies

- Replacement of a person’s income when he/she is unable to work
- Contractual in nature, as opposed to statutory
- Nature of the benefit and the scope of the rights to enjoy the benefit are set by the terms of the policy
- Can be privately purchased or provided as an employee benefit
- Short term disability/Long term disability

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Disability

- Definition can vary (because income is contractual)
- Know your contract
- Disability is usually tied to a standard of whether you can perform your job or one like it (matching your training and experience)
- Other policies may have a stricter standard, i.e. can you do any job?

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Definition of Disability

According to Social Security:

- You are disabled if you cannot do work that you did before and we decide that you cannot adjust to other work because of your condition(s), and
- Your disability is expected to last for at least one year or to result in death

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Sources of Government Paid Income

- Social Security Disability Income (SSDI)
“pays benefits to you and certain family members if you worked long enough and paid Social Security taxes.”
- Supplemental Security Income (SSI)
“pays benefits to disabled adults and children who have limited income and resources.”

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In addition, persons who have been entitled to Social Security benefits for 24 months are eligible for free Medicare benefits.

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Key Points

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SSDI and SSI Resources

- Visit SSA site for information about eligibility and approval process
- Private firms with useful web sites:
 - Allsup
 - SSLG
- Presentation by Mary Dale Walters on Social Security issues and PD

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6th Annual Young Onset Parkinson Network Conference August 7-9, 2008

- Overview and Vision for the Future
Joyce A. Oberdorf President and Chief Executive Officer National Parkinson Foundation
- Keynote Address: Hope for Tomorrow
Tom Curran News Anchor Fox 13 - Tampa Bay
- Legal Lifeline
Mark Rubin, JD Attorney at Law
- Communication Keys: It's All In The Family
Susan C. Imke, GNP-C Nurse Practitioner
- Workplace Issues: What Congress Giveth, Courts Taketh Away
Joyce Glucksman, JD Attorney at Law

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- The Genetics of Parkinson's Disease: New Targets for Therapeutic Intervention
Andrew B. West, PhD University of Alabama
- Epidemiology Meets the Internet: Building a new Approach for Parkinson's Disease Clinical Research
Samuel M. Goldman, MD, MPH
The Parkinson's Institute
- Social Security Disability: Getting What You Deserve
Mary Dale Walters Allsup
- Financial and Life Planning: Staying in Control
Paul N. Gada, JD Allsup

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Making it Work for You

- Big Picture Approach
- Importance of Self-Assessment
- Coordination with Health Care Team
- Getting the Help You Need
- Advocacy
- Look to the Future

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Dear Member of the Parkinson's Disease Community,

Together, we are asking for your help in distributing a very important form for the Parkinson's disease community. Each of our organizations has heard from people with Parkinson's disease regarding the difficulty of applying for Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI). While there can be many reasons for denial of SSDI or SSI benefits, one all too common reason is that the patient medical record, generally reviewed as part of the application process, does not contain enough information about the applicant's symptoms of Parkinson's disease that interfere with the ability to work.

To address this serious problem in our community, the Parkinson's Action Network (PAN) worked with clinicians and people living with Parkinson's to create a comprehensive form to document information about Parkinson's symptoms that may be helpful to Social Security reviewers during the application process. It is important to note that this form is designed to supplement the patient's medical record. It is not a Social Security Administration form and does not replace or change the Social Security application. A copy of the form is attached. An electronic version can also be found at <http://www.parkinsonsaction.org/PDForm>. The form was developed through a grant from Solvay Pharmaceuticals (now Abbott).

We are united in the effort to distribute this new form as widely as possible within the patient and doctor/neurologist communities. It is our goal that this form be available to further document disability for anyone who is considering applying for SSDI or SSI. Even for those who may not apply for disability benefits, this form may be useful for tracking symptoms and progression.

We ask that all members of the community help us raise awareness and distribute this new form. For example, ask that people who receive this form take it to doctor's appointments and fill it out. They can also discuss it with their doctors, share copies with members of their support groups, and/or tell others via online social networks. Feel free to use your own ideas about how to help us. Distributing the form to people living with Parkinson's, caregivers/carepartners, doctors, support groups, and online communities is essential in assuring that the form makes it into the hands of patients and doctors and ultimately into medical records. If you have suggestions for additional distribution, please contact us at info@parkinsonsaction.org or call (800) 850-4726.

We thank you very much for any help you can give us in widely distributing the attached form. It is crucial that, as a community, we do everything we can to help those for whom this devastating disease has disrupted their ability to work and support themselves and their families.



Parkinson's Disease Work-Related Disability Assessment

Through our work in the Parkinson's community, the Parkinson's Action Network has learned that people with Parkinson's may have trouble receiving Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) benefits due to inadequate documentation of symptoms in their medical record. The purpose of this form is to ensure that information that may be relevant to how Parkinson's disease affects your ability to work is included in your medical record, particularly if you think you may apply for SSDI or SSI. This form may also aid in conversation of symptoms not as commonly discussed with a physician related to a patient's ability to work. This form is not intended to offer or replace individual legal or other professional advice and should be used at your own discretion.

This form is not a Social Security Administration (SSA) form and does not replace or change the Social Security application. For more information about applying for SSDI or SSI, please visit <http://www.socialsecurity.gov/>. The SSA Parkinson's disability evaluation definition is available on the Web at <http://www.ssa.gov/disability/professionals/bluebook/11.00-Neurological-Adult.htm>.

This form may be completed by you (patient) or by your doctor and kept by your doctor in your medical record. Instructions for each are below.

Patients:

This form is designed to ensure that important medical information, from your perspective, is included in your medical record.

- Indicate who is completing the form.
- Complete the form before your doctor's visit and bring it with you. You might wish to keep a copy for your personal records.
- In the space indicated below each block of questions, please briefly explain your answers.
- During your doctor's visit, please ask your doctor to add his or her observations in the "Physician Comment/Observation" field.
- Sign and date the form and ask that your doctor do the same.
- Ask your doctor to include this form in your medical record.

Physicians:

This form is designed to ensure that important medical information about your patient is included in his or her medical record. Please discuss these symptoms with your patient and use the space provided to comment or provide your observations.

- Indicate who is completing the form.
- You may choose to ask your patient the questions as written or complete the form at the end of the visit based on the entirety of your observations and discussions.
- Fill out the "Physician Comment/Observation" field appearing at the end of each section, as appropriate.
- Sign and date the form and ask that your patient do the same.
- Include this form in your patient's medical record.

This form is available at <http://www.parkinsonsaction.org/PDform> or by contacting the Parkinson's Action Network at (800) 850-4726 or info@parkinsonsaction.org.

Created by:



With generous support from:

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Patient Name: _____ Date: _____

Form Completed by: Patient Physician Physician Name: _____

Section I: Motor Impairments

1. It is hard for me to walk.	<input type="checkbox"/> Always	<input type="checkbox"/> Often	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Rarely	<input type="checkbox"/> Never
2. When I walk, I lose my balance.	<input type="checkbox"/> Always	<input type="checkbox"/> Often	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Rarely	<input type="checkbox"/> Never
3. I have a tremor.	<input type="checkbox"/> Yes	<input type="checkbox"/> No			
My tremor interferes with my work.	<input type="checkbox"/> Always	<input type="checkbox"/> Often	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Rarely	<input type="checkbox"/> Never
4. I have dyskinesia.	<input type="checkbox"/> Yes	<input type="checkbox"/> No			
My dyskinesia interferes with my work.	<input type="checkbox"/> Always	<input type="checkbox"/> Often	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Rarely	<input type="checkbox"/> Never
5. My body stiffens periodically during the day.	<input type="checkbox"/> Yes		<input type="checkbox"/> No		
6. My Parkinson's disease (PD) makes it difficult for me to get to work.	<input type="checkbox"/> Yes		<input type="checkbox"/> No		
7. The unpredictability of responses to my PD medication impairs my ability to work.	<input type="checkbox"/> Yes		<input type="checkbox"/> No		

Explain how these or other impairments interfere with your ability to do your job.

Physician Comments – Observations/Evidence of Motor Impairment:

Section II: Physical Impairments

1. I have blurred or double vision.	<input type="checkbox"/> Always	<input type="checkbox"/> Often	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Rarely	<input type="checkbox"/> Never
2. I suffer from nausea.	<input type="checkbox"/> Always	<input type="checkbox"/> Often	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Rarely	<input type="checkbox"/> Never
3. I have to urinate frequently.	<input type="checkbox"/> Always	<input type="checkbox"/> Often	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Rarely	<input type="checkbox"/> Never
4. I drool.	<input type="checkbox"/> Always	<input type="checkbox"/> Often	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Rarely	<input type="checkbox"/> Never
5. I sweat excessively.	<input type="checkbox"/> Always	<input type="checkbox"/> Often	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Rarely	<input type="checkbox"/> Never

Explain how these or other impairments interfere with your ability to do your job.

Physician Comments - Observations/Evidence of Physical Impairment:

Section III: Non-Motor Impairments

1. I have trouble getting organized.	<input type="checkbox"/> Always	<input type="checkbox"/> Often	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Rarely	<input type="checkbox"/> Never
2. I become distracted easily and have trouble staying on task.	<input type="checkbox"/> Always	<input type="checkbox"/> Often	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Rarely	<input type="checkbox"/> Never
3. I am forgetful or have memory loss.	<input type="checkbox"/> Always	<input type="checkbox"/> Often	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Rarely	<input type="checkbox"/> Never
4. My PD makes it hard to communicate.	<input type="checkbox"/> Always	<input type="checkbox"/> Often	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Rarely	<input type="checkbox"/> Never
5. I am sleepy during the day.	<input type="checkbox"/> Always	<input type="checkbox"/> Often	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Rarely	<input type="checkbox"/> Never
6. I process information slowly.	<input type="checkbox"/> Always	<input type="checkbox"/> Often	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Rarely	<input type="checkbox"/> Never
This slow processing impairs my ability to work.		<input type="checkbox"/> Yes	<input type="checkbox"/> No		
7. I feel down or depressed.	<input type="checkbox"/> Always	<input type="checkbox"/> Often	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Rarely	<input type="checkbox"/> Never
When I feel depressed, my depression level is		<input type="checkbox"/> Severe	<input type="checkbox"/> Moderate	<input type="checkbox"/> Mild	
8. I feel anxious.	<input type="checkbox"/> Always	<input type="checkbox"/> Often	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Rarely	<input type="checkbox"/> Never
When I feel anxious, my anxiety level is		<input type="checkbox"/> Severe	<input type="checkbox"/> Moderate	<input type="checkbox"/> Mild	
9. I feel stressed out.	<input type="checkbox"/> Always	<input type="checkbox"/> Often	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Rarely	<input type="checkbox"/> Never
My stress level is typically		<input type="checkbox"/> Severe	<input type="checkbox"/> Moderate	<input type="checkbox"/> Mild	
10. I feel tired.	<input type="checkbox"/> Always	<input type="checkbox"/> Often	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Rarely	<input type="checkbox"/> Never
My fatigue during the day is		<input type="checkbox"/> Severe	<input type="checkbox"/> Moderate	<input type="checkbox"/> Mild	

Explain how these or other impairments interfere with your ability to do your job (particularly your ability to think or concentrate and your social or emotional functioning).

Physician Comments - Observations/Evidence of Non-Motor Impairment:

Section IV: Additional Physician Comments

Are there additional details relating to your patient's PD that you would like to include?

Patient Signature

Date

Physician Signature

Date