

PARKINSON

REPORT

1-2

Depression Drives
Quality of Life
in Parkinson's

3

Caring for the Caregiver

4

Aware in Care:
Making a World
of Difference

5

What's Hot in
Parkinson's Disease?

6-7

Top Questions
and Answers from
"Ask the Doctor"

Caregiver Tips
for Daily Living

8

A Caregiver Heroine
in Fiction and Real Life

9

Moving Toward
the Best Life

10

Free NPF
Webinar Series

11

Support NPF

Depression Drives Quality of Life in Parkinson's:

NPF Releases New Report to the Community



Although Parkinson's disease (PD) impairs many aspects of movement, it's the disease's impact on emotions that has the greatest effect on quality of life. The first report to the community from the National Parkinson

Foundation's Quality Improvement Initiative, part of the Parkinson's Outcomes Project, has found that depression is the number-one factor influencing health status. Based upon this report, and other research, NPF recommends that all people with Parkinson's get screened for depression at least once a year.

What Works Best in Parkinson's Care?

The Parkinson's Outcomes Project was created to help researchers identify what treatment and care strategies have the greatest impact on lessening the symptoms of Parkinson's by studying the differences in care provided by leading experts. At the project's core is a comprehensive database of information on more than 5,000 patients, who have been evaluated in the clinic by expert neurologists, and followed in 20 NPF Centers of Excellence around the country and the world.

"Through this report, we wish to start a conversation with the patient community about what works best in Parkinson's care," said Joyce Oberdorf, NPF's President and CEO. "We believe that the best expert care can mitigate the impact of Parkinson's disease and significantly improve quality of life. Ultimately, the goal of the Parkinson's Outcomes Project is to make it possible

...continued on page 2

**NOVEMBER IS
NATIONAL FAMILY
CAREGIVERS
MONTH**

Caring for the Caregiver

"If the caregiver collapses, everyone loses..."
...continued on pg 3

Aware in Care

"Having the *Aware in Care* kit has made a world of difference."
...continued on pg 4

A Caregiver Heroine

"Caregivers don't realize how strong they are."
...continued on pg 8

Depression Drives Quality of Life in Parkinson's: NPF Releases New Report to the Community

...continued from cover

for every person with Parkinson's to gauge how well their care measures up and to choose treatments based on solid evidence, not guesswork."

Key Findings:

1. NPF has found that patients at some centers fare better than similar patients at other centers. We don't know why this is, but we believe it is a combination of two things: doctors at some centers are getting referred patients who are simply doing worse to begin with, and the centers with the best outcomes are providing a superior level of care that leads to better outcomes.

2. NPF has found that most centers use medication differently. Once Parkinson's advances, physicians rely on their best judgment in managing drug regimens. As a result, patients who seem to be very similar can be on very different prescription regimens. What we have found is that some neurologists opt for more complex and individualized medication strategies, while others prescribe simple treatment plans of one or two medications.

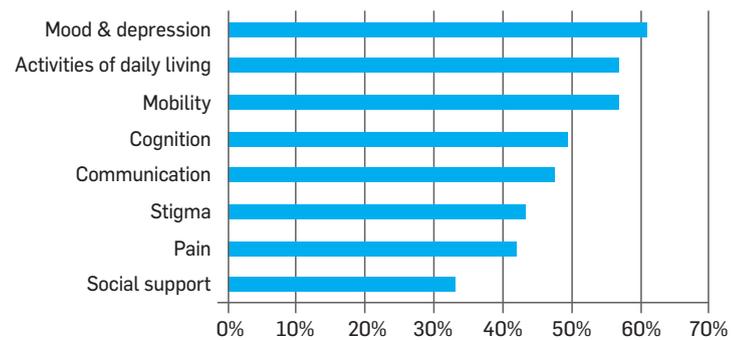
3. Finally, NPF has found that centers also refer patients to allied health professionals differently. Sometimes this is due to varied philosophies about the range of care they offer their patients and at other times it is due to issues surrounding access to care. We have found that depression, for example, seems to be treated best when patients are referred to a counselor, yet not all centers follow this approach.

Depression: Too Often Untreated

Referring a patient diagnosed with depression to a therapist for treatment is paramount because negative mood and depression are the most important factors contributing to the health and wellbeing of someone living with Parkinson's (see chart in next column). For doctors, however, diagnosing depression can be difficult because some symptoms of Parkinson's—such as a masked facial expression, sleep problems and fatigue—overlap with symptoms of depression. In fact, studies show that the majority of people with Parkinson's will go unrecognized or undertreated for depression.

That's why individuals must understand that depression is a disorder, not a character flaw, and discuss even subtle changes in mood with their doctor as soon as they arise.

Overall contribution to health



NPF has found that measuring depression and mood in people with PD is the best way to understand the big picture of a person's health.

Parkinson's disease affects chemicals in the brain that are responsible for the way we feel, so depression can be caused by the underlying disease process. Ongoing stress, sadness and social isolation that result from living with a chronic disease can also trigger, or worsen the condition.

"It's very important that depression is considered just as important as any of the other physical symptoms of Parkinson's," said Michael Okun, MD, NPF's National Medical Director. "As this report shows, improving mood is one of the most significant ways to address the other aspects of Parkinson's."

NPF recommends a comprehensive, holistic approach to depression. Treatments with antidepressant medications, independently, or in combination with exercise, psychotherapy, and behavioral techniques, are very effective. "Cognitive behavioral therapy—teaching coping strategies, building on self efficacy, and thinking positively—is a very important part of a person's overall wellness," Dr. Okun said. "Each individual's treatment plan should be tailored to their symptoms, preferences and other illnesses."

As NPF researchers continue to analyze this growing collection of data, they will establish a standard of care that has been "tried, true and tested," and can inform proactive treatment plans. Ultimately, the purpose of the Parkinson's Outcomes Project is to help people who have Parkinson's to not only live longer, but also healthier, more active lives.

To read the full report to the community, NPF's Parkinson's Outcomes Project, visit www.parkinson.org/outcomes.