

What to do when bad news isn't understood?

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LIKE MOST CLINICIANS, I have to give people bad news. Not every day, but often enough. My first task with a new patient is to provide a diagnosis. I need to tell patients the name of their disorder. I have to explain what is known about the disease, its causes, its treatments, and, of course, the prognosis. Luckily, only rarely do I have to give them the worse news that their children may get what they have as well, inducing guilt in addition to the distress of worrying about their own body. There are occasional happy diagnoses as well, just not so many. "That sensation of tremor is common. It's not a premonition of a significant problem. Not to worry." Most of my patients are prepared for an unwanted opinion, hoping they have essential tremor but worried that they really have Parkinson's disease (PD), and sometimes equipped in advance with the name of a doctor in Boston for a second, hopefully more acceptable, different opinion.

Most patients receiving the diagnosis of PD or a related disorder are stoic in the office, although clearly saddened and frightened. Their response is what you would expect when the ground is cut out from under your feet. This case was different. The patient was under 40, and came because of progressive slowness. She knew there was something wrong,



but didn't seem to be too bothered. She had signs of parkinsonism, but without tremor, and I thought this was most likely psychogenic, because some exam findings I thought inconsistent. Perhaps I was, in part, influenced by a small degree of "belle indifference." I know that "belle indifference," a patient's seeming disinterest in their disability, is not a reliable sign of a psychogenic disorder, but, like many unreliable signs, there is often a kernel of utility. She didn't seem to be alarmed by her problem. She was seeing me because she recognized that something was amiss, and ought to have it corrected. I have learned to share my thoughts on the possibility of a psychogenic diagnosis with patients early on to give them time to accept it, as many patients are very reluctant to do so and get angry at the doctor when the diagnosis is suddenly sprung on them, saying, "You think it's all in my head? Well, you're crazy, not me!" Usually I think that if I plant the seed, explaining my reasoning, and include it as a consideration, along with physiological disorders, that the patient is more likely to accept it, realizing it's a much better diagnosis to have than my usual offerings of incurable, neurodegenerative disorders. As is often the case, I wasn't completely sure it was psychogenic and ordered a dopamine

transporter (DaT) scan, which provides a crude estimate (normal or pathologically reduced) of the number of brain cells which make dopamine. This test should be abnormal in PD and related disorders, and, if normal, indicates the diagnosis is not PD. Her test was abnormal. I was wrong to think it was not physiological but correct in ordering the test. I almost always give DaT results in person, because, for most people, a positive result, an abnormal test, indicates that the patient has PD or something worse. I do not think this should be given over the phone in most cases. We need to discuss this in person, with a support person present, as well. I therefore had the very unfortunate duty of informing this young adult that not only was I going to ruin her day, but also her life. Doctors do this all the time. It's one of the "downsides" of the profession. It's certainly not unique to my line of work.

When I told her, she didn't bat an eye, and reacted as if it was good news that we knew the diagnosis. She apparently knew nothing of PD, had no idea this was incurable, and, in a high percentage of cases, disabling. I expected that she would be crushed. She would cry, bemoan her fate, and ask me if there might be an error. But no. She figured if there was a disease, there was a treatment. I explained some things about the illness, and gave her a prescription, clearly stating that this was symptomatic therapy which would not treat the

actual disease process. I explained what that meant. I explained that this was often a serious disorder. And I underscored multiple times the importance of contacting the nurse at our PD information center. I then contacted the nurse, myself, to outline the situation and have her try to figure out some way to lead the patient to understand, in as supportive manner as she could, the seriousness of her diagnosis. And I scheduled her to see me again fairly soon, to give her time to learn about this, but not too much time.

It is a rare event for someone to be nonplussed by a serious diagnosis. In her case it was due to her lack of knowledge. I did not think this was a form of agnosia, a technical neurological term that denotes an inability to appreciate a neurological deficit. I doubted the wisdom of my simply explaining the gravity of her situation. I thought it better that she read about the illness, slowly, hopefully, and accommodate to the change

in her life. I know that there is no single “correct” way to tell patients a diagnosis. Different patients require different approaches, all based on the principle that doctors need to be sensitive. We need to tell them the truth in as supportive a fashion as possible, explaining that we will fight this problem together and do our best. That can’t happen when the patient doesn’t appreciate the problem. I wanted to be comforting, to explain my role, the importance of exercise, the fact that this illness progresses in very different ways in different people, that we’d work together. But there was no there there. She was not in distress, nor was she in denial. She was in a world where she had a minor problem and I didn’t think destroying her cocoon was a good idea at that time. I worried more about her than about my patients who break down crying, asking, “Why me?”

I don’t know what I was hoping her to be like when I saw her next. When

she came back, she had read about Parkinson’s disease, and appeared to understand her situation, although not in its full gravity. The gravity of the disorder was partly counterbalanced by her improvement on medications. It was a relief to me. We were now playing in the same ballpark and we both now understood the rules. ❖

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Caring for Caregivers: Burnout and Resources for Caregivers in Rhode Island

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"I just need a break. I can't leave the house because I'd feel nervous something would happen to my husband when I'm not there. Doctor, coming to see you is my break, and he's even waiting for me in the waiting room. This is my life now, isn't that sad?" You may not have met Sarah, the 77-year-old woman who cares for her husband with Alzheimer's disease. But you know her. Sarah is the person we may all become, and the person we one day will surely count upon. Sarah is a caregiver.

According to the Rhode Island AARP, at least 148,000 Rhode Islanders are unpaid caregivers for loved ones, friends, or neighbors.¹ As a state and as a country, we lean on our caregivers to provide care to those among us who are chronically ill, helping our sickest patients spend their last days, or years in the case of Alzheimer's disease, at home in relative comfort. For all too many patients like Sarah, their often all-consuming role can overwhelm and lead to burnout. One study showed that as many as 75% of caregivers struggle with symptoms characteristic of anxiety and depression.² This strain on mental health leaves lasting impacts on the physical health of caregivers. Among elderly caregivers, one study found that those experiencing significant emotional distress from their role had a 63% increased risk of four-year mortality compared to their non-caregiver counterparts.³

As a community, we as medical providers may at times feel stuck, wondering how we can offer support to our patients like Sarah, unsure of how to make the weight of their world a little bit lighter. As part of an Alpert Medical School master's course in population and clinical medicine, we queried a group of 14 primary care providers (a mix of MDs and social workers in a primary care setting) in Rhode Island to obtain a sense of pre-existing knowledge of caregiver resources. On a scale of 1–5, with 1 being minimal familiarity, the healthcare providers rated their familiarity with existing resources for caregivers at a 1.5 out of 5. To broaden the awareness of caregiver resources, we delved into a selection of caregiver support programs as highlighted in the following sections. The appendices at the end of the section include additional links to information and application forms for discussed programs.

Care Breaks Program

Managed by the Diocese of Providence, this program, which is offered to people of all faiths, assists caregivers in scheduling and financing temporary caregiving alternatives, such as a home health visit, so caregivers can have a short break from their caregiver duties to attend to their own needs. Care Breaks is a cost-sharing program with graduated assistance based on income. Applicants must be Rhode Island residents caring for a disabled adult or child and not receiving other respite assistance from another state or federal program. The respite coordinator for the Rhode Island program can be contacted at 401-278-2511. The following links provide more information and applications.

Powerful Tools for Caregivers Program

A standardized, evidence-based curriculum available in Rhode Island, this program helps provide caregivers tools to communicate in challenging situations, make difficult caregiving decisions, and manage personal stress. The program is led by two certified peer leaders in weekly 2.5 hour group sessions over the course of six weeks. Participants receive The Caregiver Help Book, which is specifically designed for the course and contains guidance on, among other topics, issues related to medical aspects of caregiving, emotional and intellectual well-being, and legal and financial affairs.⁴ This program is free of charge and without any income requirements. Interested caregivers can contact the elder services outreach coordinator of the Diocese of Providence at 401-278-2528 and find more information and a calendar of any upcoming sessions here.

Alzheimer's Association of Rhode Island

Dedicated toward assisting those suffering from Alzheimer's disease and their families, the Rhode Island chapter of the Alzheimer's Association offers a wealth of resources. Their 24-hour helpline at 1-800-2272-3900 offers free caregiving tips, respite-care options, and information on resources available in patients' communities. The Alzheimer's Association hosts local support groups for Alzheimer's disease patients, their caregivers and families. Additionally, the Association's Early Stage Social Engagement program helps newly diagnosed patients navigate their new diagnosis, tools for maintaining a physically and mentally active life, all while giving their caregivers an opportunity for a break. Those interested can learn more about the Alzheimer's Association's resources here.

Rhode Island Caregiver Resource Manuals

To learn more about the resources already outlined and others, the Rhode Island Department of Elderly Affairs (DEA) arranged an easy to navigate “Pocket Manual for Seniors and Adults with Disabilities.” For a guide more concretely geared toward caregivers, the DEA’s “Guide for Caregivers” offers tips and resources organized by the age of the patient for whom a person is caring.

The challenges caregivers face are enduring and seemingly insurmountable, but they need not be borne alone. Armed with the knowledge of resources that are accessible to our patients and family members, the Rhode Island medical community should be equipped to offer aid to their patients like Sarah. In busy medical practice settings with competing priorities and time pressures, office support staff and allied professionals under physician direction may provide patients with information on available supports. Too often, our patients come to us feeling stuck, and we can and should empower them.

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Disclaimer

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Appendix A:

Additional High-Yield Resources for Caregiver Support

Start Here: RI Division of Elderly Affairs <http://www.dea.ri.gov/>
National Caregivers Library <http://www.caregiverslibrary.org>

Target Demographic for Caregivers

1. Children

- Special Issues: Individualized Education Programs
- Organizations: Parent Support Network of Rhode Island: www.psnri.org, Rhode Island Department of Health, Office of Special Health Care Needs: www.health.ri.gov/specialhealthcareneeds

2. Teenagers

- Special Issues: Parent Advocacy Groups
- Organizations: Rhode Island Parent Information Network: www.ripin.org, Rhode Island Department of Behavioral Healthcare, Developmental Disabilities and Hospitals: www.bhddh.ri.gov

3. Adults

- Special Issues: Money Management, Children at Home
- Organizations: The Point: <http://www.dea.ri.gov/CIS%20Info/index.php>, Financial Planning Association of Rhode Island: www.fpari.org, U.S. Government Disability: www.disability.gov

4. Older Adults

- Special Issues: Independence, Assisted Living
- Organizations: Diocese of Providence Respite Services: www.dioceseofprovidence.org “Elder Services”, Rhode Island Division of Elderly Affairs: www.dea.ri.gov

5. Veterans

- Special Issues: Government vs Private Benefits
- Organizations: Rhode Island Division of Veterans Affairs: www.vets.ri.gov, U.S. Department of Veterans Affairs: www.va.gov

Caregiver Tips

1. Self Care

- Tips: Listen, Ask questions, Encourage Independence, Ask for Help, Get Support, Take Breaks, Be Kind to Yourself
- Resources: National Caregivers Library: www.caregiverslibrary.org

2. Working

- Tips: Temporary Caregiver Insurance, Family and Medical Leave Act, Rhode Island Parental and Family Medical Leave Act
- Resources: American Association of Retired People: www.aarp.org/caregivingbook, Rhode Island Department of Labor & Training: www.dlt.ri.gov. Click “Temporary Caregiver Insurance”

3. Financial Planning

- Tips: Financial Literacy Classes, Personal Financial Planner, Personal Lawyer, Temporary Disability Insurance, Social Security Disability, Supplemental Security Income
- Resources: Financial Planning Association of Rhode Island: www.fpari.org

4. Legal Documents

- Tips: Advanced Directives, Living Wills, Power of Attorney, Medical Orders for Life-Sustaining Treatment, Guardianship
- Resources: Rhode Island Department of Health: www.health.ri.gov. Click “Topics & Programs” and then “Advance Directives”, Rhode Island Bar Association: www.ribar.com

5. Emergency Plan

- Tips: Basic Health Information, Medicine, Allergies, Advanced Directives, Legal Documents
- Resources: Healthcentric Advisors: www.healthcentricadvisors.org/myccv



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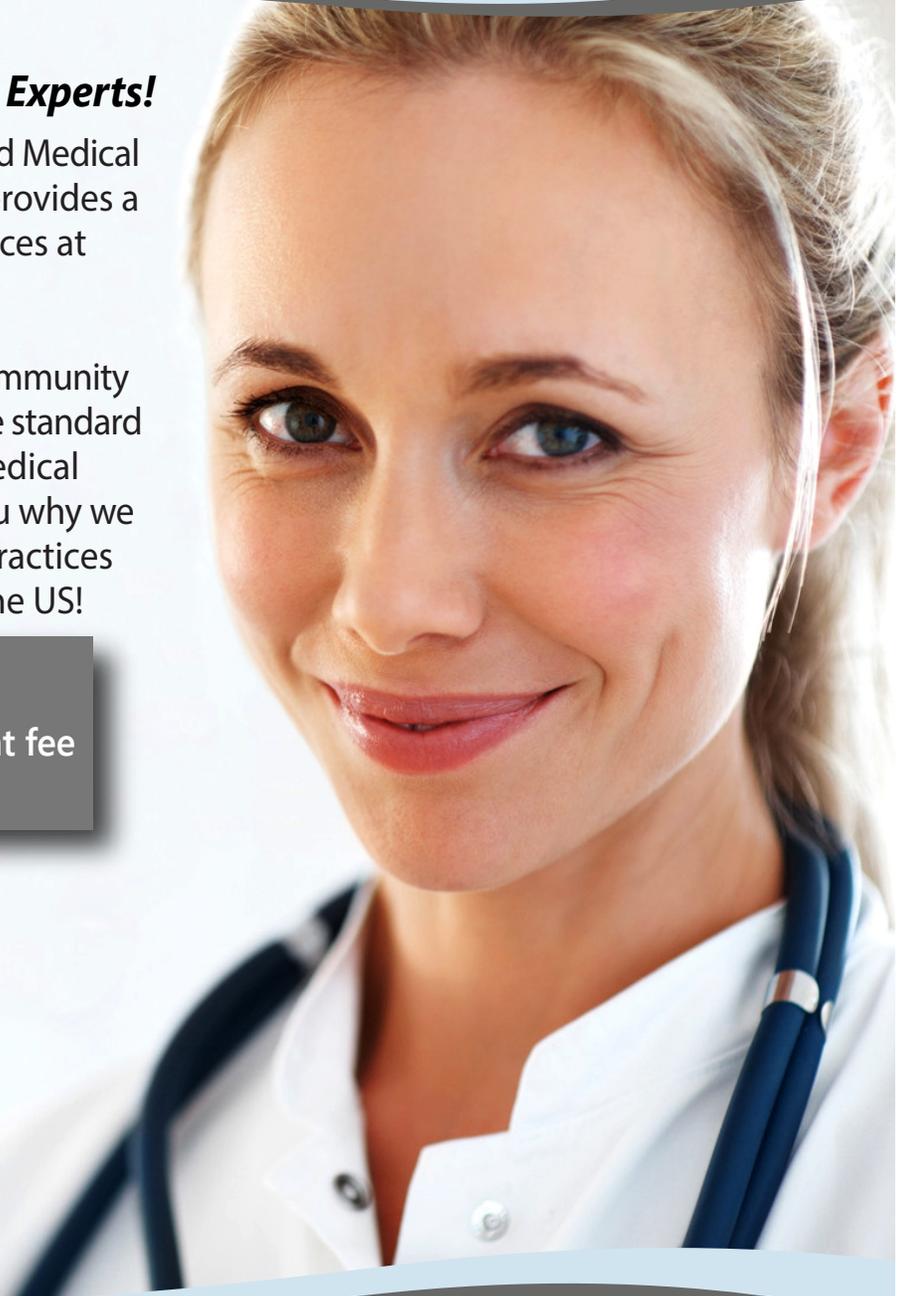
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