

Timely Compassion for Early-Onset Alzheimer's Disease

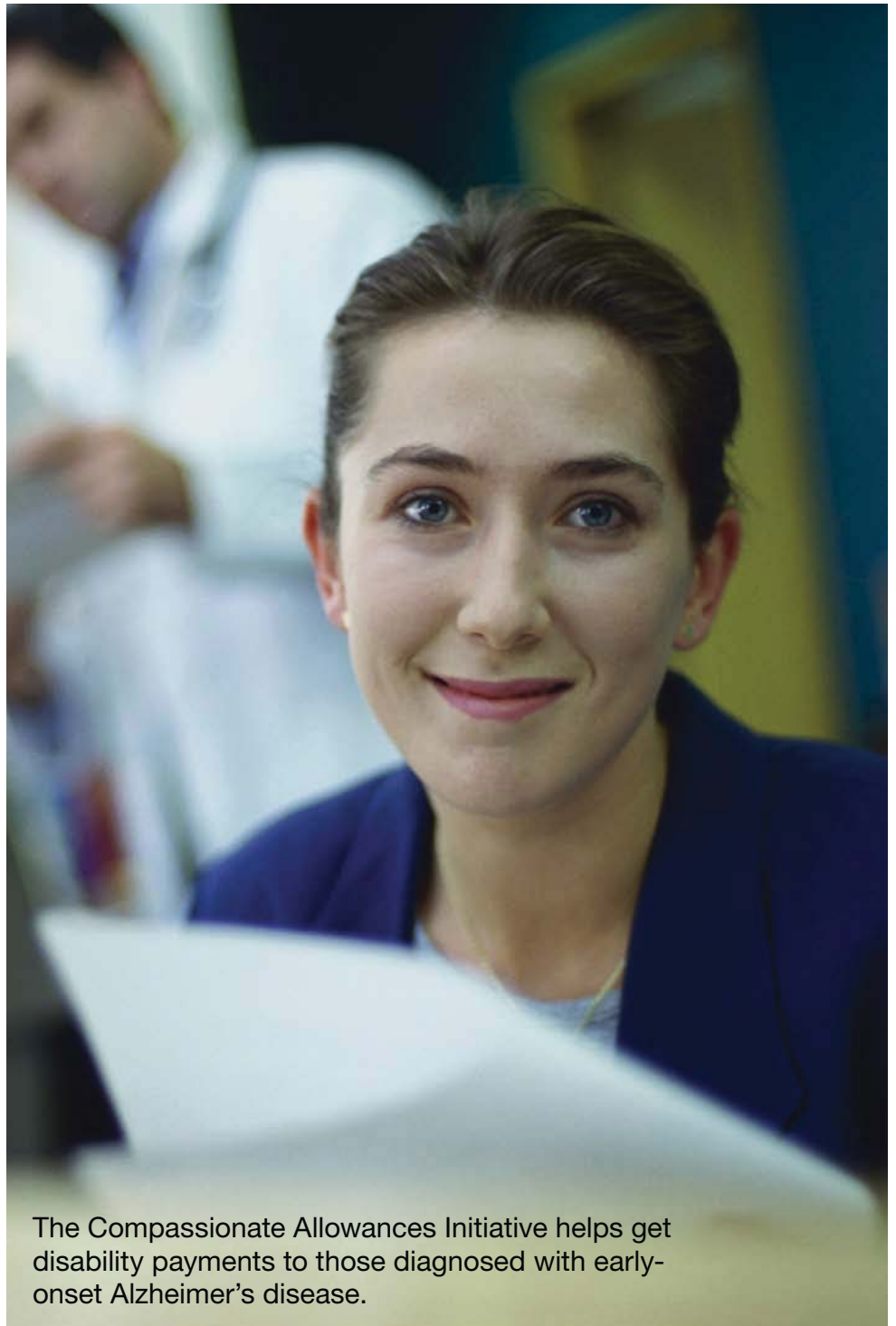
Only the elderly get it—or so most people think. But Alzheimer's disease can also hit people in their 30s, 40s and 50s. If you're under 65, it's referred to as early-onset (or younger-onset) Alzheimer's disease. It's bad enough when you're only 50 and can't work or properly care for your family because you've got Alzheimer's. Do you also have to struggle fighting for Social Security benefits?

Not anymore. On February 11, 2010, the Social Security Administration included, for the first time, early-onset Alzheimer's disease in its Compassionate Allowances Initiative. The computerized system helps get disability payments to people more quickly than ever.

Before the Compassionate Allowances Initiative, if you were diagnosed with early-onset Alzheimer's disease and you applied for disability, you may have battled Social Security's long-drawn-out decision process, disappointing denials and daunting appeals. For many, the process was a financial and emotional drain. "Now, if you're eligible, you can get approved for benefits in as little as 14 days, rather than months and years," says Dorothy J. Clark, Social Security spokesperson.

Recognizing the Need

The need for Social Security to speed things along got the Compassionate Allowances Initiative going in the first place. It was first introduced in October 2008. By then, Social Security had arrived at the Initiative's list of 50 medical conditions (25 rare diseases and 25 can-



The Compassionate Allowances Initiative helps get disability payments to those diagnosed with early-onset Alzheimer's disease.

cers) that were most likely to meet their current definition of disability. They came up with this list based on information they gathered at public outreach hearings, and from the Social Security and Disability Determination Service communities. They also turned to medical and scientific experts.

“Subsequent to launching the original 50 conditions, we expanded our focus to look at subgroups of much broader conditions,” says Clark. One of them was early-onset Alzheimer’s disease.

And for good reason. Most people with Alzheimer’s are 65 and older. But more and more people younger than that are also getting the disease. For many with Alzheimer’s, whatever the age, Social Security disability benefits make up their sole source of income. If only most people with this disease weren’t so afflicted, they would probably be able to hold down a job. But how can they? Often their memory is too impaired, sometimes even at the earliest stages.

Because Alzheimer’s typically first affects the part of the brain that deals with learning, if you have this disease, you may not be able to remember new information. Over time, as the disease marches through your brain, it leaves in its wake mental disorientation and behavior changes, confusion, suspicion about those who don’t deserve it, worsening memory loss and, eventually, trouble speaking and walking. While loved ones and health care providers may easily recognize the symptoms, people with early-onset Alzheimer’s disease might never know they’re sick.

This rapidly progressive and incapacitating disease “clearly deserved our consideration,” says Clark.

On July 29, 2009, Social Security held an all-day Compassionate Allowances Hearing on Early-Onset Alzheimer’s Disease and Related Dementias, in Chicago. Several of the country’s top Alzheimer researchers spoke, as did caregivers and those with the disease. Social Security decision-makers listened to them talk



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about the lack of a cure, or inefficient treatment to effectively help heal or halt the disease. They also heard about the mental limitations that prevent someone with early-onset Alzheimer’s disease to have a job and make money.

The Social Security Administration was convinced. On February 11, 2010, the agency announced the first expansion to the list of Compassionate Allowances since the Initiative’s launch. Thirty-eight severe medical conditions were added—from rare, childhood diseases to adult brain disorders, including early-onset Alzheimer’s disease. The list also included other, related dementias (Pick’s disease, Creutzfeldt-Jakob disease, mixed dementia and primary progressive aphasia).

Speeding the Process

The new addition brought relief for many with early-onset Alzheimer’s disease. The Compassionate Allowances Initiative has done its job well from the beginning. For starters, it’s built as a fast-track system. When you apply, the system

electronically identifies your disability, based on what you put in your application. Once Social Security labels your case as a Compassionate Allowances one, then the agency seeks out minimal—but sufficient—objective medical information.

The Compassionate Allowances Initiative also simplifies and streamlines your ride through the disability-claim process. The Initiative’s inclusion of early-onset Alzheimer’s disease expedites the processing of Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) claims for applicants with this disease.

Of course, you still have to meet other SSDI and/or SSI criteria. For instance, if you have early-onset Alzheimer’s and also have been employed the required number of years, you’re entitled to receive monthly SSDI benefits (after a five-month waiting period). Depending upon your income and resources, you may receive SSI payments. Once qualified for SSI, the agency will give you the go ahead to get those badly needed benefits. Benefits you deserve.

Early-onset Alzheimer’s disease will eventually be joined by even more, equally serious illnesses in the Compassionate Allowances Initiative. Says Clark, “We are continuing to hold hearings and look for other diseases and conditions that can be added to our list.”

Social Security’s offering of financial assistance to those at such a difficult time of their lives will only help millions of people endure challenges that otherwise may have devastated them. Certainly, it’s the compassionate thing to do. ■

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