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Reconsidering psychiatric drugs

By: Susan Palmer

Jan. 28--When the anti-psychotic drug Zyprexa came into Tracey Dumas' life five years ago, it sounded like a good thing: a relatively new medication that would relieve her psychotic thoughts without the damaging side effects of the old drugs. Dumas was willing to try it.

But like many of the powerful class of neuroleptics that target the symptoms of mental illness, Zyprexa had problems. After a year of taking it, the normally petite Dumas had gained 90 pounds and had developed pre-diabetic symptoms, an illness that did not run in her family.

While the drug seemed to calm her delusional thoughts and didn't make her feel as sluggish as some other medications, it was also ruining her health.

Now, like thousands of others, Dumas is part of a class-action lawsuit against Zyprexa manufacturer Eli Lilly, which already has spent \$1.4 billion to settle more than 20,000 claims by patients who say the drug made them sick.

Oregon Attorney General Hardy Myers is one of five attorneys general investigating whether Eli Lilly illegally promoted uses of Zyprexa that have not been approved by the U.S. Food and Drug Administration.

And the pharmaceutical company also is embroiled in a court battle over online access to its internal documents that suggest Eli Lilly knew and deliberately obscured the drug's side effects to keep sales high.

That possibility angers and saddens Dumas, who said she has no interest in financial gain from the suit.

"These drugs have a permanent lasting effect. I have neighbors and friends who have ballooned up and have diabetes because some drug company wants to make money. People's lives are not considered," she said. "I want for them to be held accountable."

Eli Lilly spokeswoman Carole Puls said the company provided information about Zyprexa's side effects to physicians from the time the drug first went on the market in 1996. The company chose to settle the product liability suits because it was in everyone's best interest to do so.

"We remain confident that the claims are without merit," Puls wrote in an e-mail response to Register-Guard questions. "Our decision to resolve the claims does not change the fact that Zyprexa has and will continue to improve the lives of

millions of patients around the world who are suffering from schizophrenia and bipolar disorder."

The Zyprexa suits come at a time when many people are questioning the role of anti-psychotic medications in caring for those with psychiatric diagnoses and demanding that people experiencing the symptoms have more of a say in their treatment.

The history of the drugs is checkered with problems, said Dr. Grace Jackson, a former Navy psychiatrist whose book "Rethinking Psychiatric Drugs" delves into the medications.

Neuroleptics first came on the scene in the 1950s, she said, as psychiatrists were discovering that sedating agitated patients in asylums and hospitals seemed psychologically beneficial.

Then a French military surgeon investigating a compound that came to be known as Thorazine passed it on to a psychiatrist friend who began testing it on psychiatric patients.

It had a profound effect -- subduing their agitation -- but it came at a cost. The drug also causes involuntary abnormal movement -- hand tremors, a shuffling gait, twitching facial muscles, fluttering tongue -- in a condition known as tardive dyskinesia. In some patients, the condition was permanent, lasting even after the drugs were discontinued.

When a new class of neuroleptics that did not seem to cause involuntary movement was developed in the 1990s, psychiatrists quickly added them to their treatment options, Jackson said.

Then history repeated itself. As people began to use them, alarming side effects emerged, including a range of metabolic changes such as weight gain, increased blood sugar, precursors to diabetes and the onset of diabetes itself.

"The whole history of these drugs is just based on symptomatic trial and error empiricism rather than a rational theory," Jackson said.

Dumas knows the history intimately. She's lived it. At 58, she is calm, intelligent and thoughtful, a woman whose easy smile betrays no hint of the self-destructive power of her own thoughts.

But she estimates that she's been hospitalized at least 60 times, the first time at age 18 when crippling depression made her suicidal. She's had electroshock therapy and been prescribed many neuroleptic drugs and anti-depressants.

The drugs were meant to help her control the dangerous spiral of thinking that would start with debilitating depression then drag her toward suicide or delusions that someone was trying to kill her.

Sometimes she believed she was responsible for the bad things that happened to others. Sometimes her thinking was so disjointed that she could barely put a sentence together. Sometimes her thoughts pulled her so far down she tried to take her own life.

Dumas was prescribed many of the first generation of anti-psychotics: Thorazine, Stelazine and Mellaril. Her doctor cycled her through them looking for the one that would ease her symptoms with the fewest side effects. But like many other patients before her, Dumas experienced the involuntary movements, a fluttering tongue, her eyes rolling up into their sockets. The result: People stopped seeing her and started seeing her symptoms.

"These are the things that people notice about you," she said. "You go to a job interview. Your knee is jerking; they notice that."

But the drugs and periods of hospitalization seemed better than the alternative -- the dark thoughts that led her to isolate from others, and that, uncontrolled, led to suicide attempts.

While Dumas had periods when she was able to function -- she recently completed a doctorate in sociology at the University of Oregon -- there also have been times when her thoughts were so disordered that electroshock therapy, a treatment reserved for only the most psychologically troubled, seemed like a good idea to her.

Her experience of the drugs: They didn't make her symptoms go away, they just made her so groggy that she stopped feeling much of anything.

None of the drugs used to treat psychiatric disorders actually cures people, because doctors still don't really know what causes the disorders.

Psychiatrists and neuroscientists say that biochemical imbalances in the brain are behind the range of conditions that include mood disorders such as bipolar disorder, and the delusions and hallucinations of schizophrenia.

But the specific details are still unclear, said William Wilson, a psychiatry professor at Oregon Health & Science University.

"We don't know what schizophrenia is. We do have a lot of the puzzle pieces. It's kind of like where cancer research was several years ago. We have plenty of notions about where to look, and I have a lot of confidence in neuroscience sorting it out as long as the funding is there," he said.

But Jackson says researchers came to the biochemical conclusion via a process of faulty reasoning, figuring that because the neuroleptics had an impact on brain chemistry, brain chemistry must be the source of the problem.

There's a downside to telling people that they have a chronic brain illness, said Al Levine, program manager at Lane County Mental Health. "In many ways, it's a

disempowering message," he said. "We often did people a disservice by setting up over-dependency on mental health treatment."

Levine said the jury's still out on what causes the conditions. "For some mental illnesses, there are some real discernible biochemical changes in the brain. ... But it's also true that some symptoms we call mental illness are maladaptive responses to early life events."

Dumas believes that is true for her. She said she was a victim of repeated sexual, physical and verbal abuse as a child, and was raped as a young woman. She also suffers from post-traumatic stress disorder, she said.

Last year, she finally grew tired of the regimen of drugs and hospitalizations, and she sought out new options -- peer support groups, art therapy, counseling, improved nutrition and exercise.

She found the inspiration for change at Safe Inc., a drop-in center for people with similar problems.

"Tracey's stubborn," said Drake Ewbank, outreach care coordinator at Safe. "She was tired of being on medications, of being a vegetable, being in crisis or over-medicated. She's got a lot of strength of character."

Safe does not advocate that people stop taking their medications, Ewbank said. But it does give people the opportunity to share their experiences with each other, and that was key for Dumas.

"I started seeing more hope, seeing the example of people on little or no meds. I had been told I would never be able to be off these drugs," she said.

No one big thing changed in her life. It was a bunch of little things. Her doctor slowly reduced the dosage of her drugs. She began reading and knitting, finding a kind of safety and relaxation in the repetitive nature of the task. She took more care with her diet, eating nutritious foods and supplementing with products such as fish oils that some research suggests has beneficial effects.

And she learned that she could stop the progression of dark thoughts before they overwhelmed her. Sometimes she is able to substitute other thoughts, and sometimes she does something active, such as going for a walk.

But the most useful change has been discovering that she can be a help to others. Dumas has started serving on committees that work on issues not just in the mental health world but in the area of domestic violence.

She was recently named president of the board of the Trauma Healing Project, an ad hoc committee affiliated with Womenspace in the process of becoming an independent nonprofit.

She has organized meetings that bring together police, health care workers and the community to address the problem of abuse of the disabled.

Last week, she joined a state-sponsored project that will help her train people with psychiatric disorders to better communicate with their caregivers, and to understand they have rights and can ask questions about the drugs and other care options available to them.

Dumas won't advocate that people refrain from taking neuroleptic drugs. It's not her place to push any particular agenda, she said.

"I want them to come to recognize they have some choice, they have power, they have a voice."

The notion that the mentally ill have options and have a say is gaining ground, said Levine, who has worked in the mental health field for 30 years.

"And there's been a big push in nontraditional approaches, everything from body work to acupuncture to massage therapy to teaching relaxation techniques," he said.

Safe Inc. is a prime example. It evolved from a purely peer support drop-in center with an art gallery and performance space to a fully certified mental health treatment program with psychiatrists and prescription-writing capabilities.

Laurel Hill Center also has a drop-in program, Pathways, that provides a range of classes from money management to exercise.

While such alternatives broaden the scope of options, the money to support them is still lagging, said Wilson, the OHSU professor.

"It's very easy for me to write a prescription for thousands of dollars worth of drugs and very difficult to get the most basic kinds of rehabilitation," he said.

Last year, Oregon Medicaid -- a blend of state and federal funds that pays for treatment for mentally ill residents with no health insurance -- spent \$75 million on mental health drugs.

"We're finding there are so many restrictions on what you can spend Medicaid dollars on, you don't find the flexibility you need when you're dealing with a person in a holistic way," Levine said. "It's a battle every step of the way."

Few people expect that the anti-psychotic drugs -- problematic as they are -- will be completely eliminated. They still have a role to play in stabilizing patients whose thoughts are so out of control that they are a danger to themselves or others, Wilson said.

"I don't think we'll see things going to nondrug treatment, but there will be a lot more emphasis on social aspects, on person-centered recovery efforts, which would decrease the overall amount of drugs used," he said.

