**Side Effects: Rules meant to combat the opioid crisis are leaving chronic pain patients to suffer**

Part one of a two-part series.

CHESAPEAKE - Charles Grose took a sip of Diet Coke and leaned back in his worn recliner to rest for a few minutes before leaving for the appointment that he'd been thinking about for the past three months.

Earlier that morning, his wife, Debbie, had attached two of his remaining 50-microgram fentanyl patches to his left arm, and he'd felt relief.

He'd worn his last pair of patches for four days, twice as long as the dose of the powerful synthetic opioid was meant to last, and the pain that shot from his hip to his feet, that ached deep in his shoulder joints and stabbed down his spine, had returned.

The 60-year-old had been squeezing as much relief out of his medication as he could ever since the pain management doctor he'd been seeing for regular prescriptions told him in December that she would be tapering him off opioids to comply with prescribing regulations from the Virginia Board of Medicine that took effect in August.

The painkilling drugs he needs for relief are at the center of a public health emergency in Virginia and across the U.S. Fentanyl has become the state's deadliest drug, and, in the past six years, 5,852 people in Virginia have died of an overdose on opioids, a class of opium-like drugs that includes prescription painkillers and heroin.

In response, state and federal authorities have worked to reduce prescriptions to limit the supply of the deadly drugs along with the number of people taking them.

The federal guidelines and state regulations have led some health care providers to cut off patients who have severe, chronic pain, leaving them scrambling to find a doctor who will offer them relief.

One Richmond doctor who specializes in addiction treatment says he's been seeing "pain refugees," people who've lost access to their medicine without being given an alternative.

And a group of pain patients - representing some of the 20 million people in the U.S. with severe chronic pain, according to the Centers for Disease Control and Prevention - held a "Don't Punish Pain" rally in front of the Virginia Department of Health building in January to protest what they see as overregulaton of prescribing.

The same group has another rally planned for May 22 on the steps of the Virginia State Capitol.

Last month, the CDC, which published prescribing guidelines for opioids in 2016, acknowledged that the guidelines have been misapplied to the detriment of pain patients, and the Virginia Board of Medicine said it's encouraging prescribers to gain a better understanding that the rules still allow opioids to be prescribed for pain, as long as it's documented.

But patients, like Grose, continue to be cut off as doctors move away from prescribing the drugs that could put their patients - and their practices - at risk.

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In 1985, Grose was driving home from work in his Ford Granada sedan when a construction truck suddenly cut him off. He swerved to avoid the truck, but slammed into a water truck on his left instead. First responders had to use the Jaws of Life to cut him out of his crumpled car. He walked away with dislocated ribs and a broken thumb, lucky to be alive.

A year later, Debbie was driving Grose home after they'd gone out to dinner. When they were just a few blocks from their Chesapeake home, a car swerved into their lane and hit them head-on at 90 mph, just as Grose had unbuckled his seat belt to reach for the radio.

Grose flew through the windshield, slicing off his right eyelid and part of his face, injuries that would require reconstructive surgery. From then on, he would deal with pain in his back and neck.

For nearly 15 years, Grose attempted to manage his pain with the help of a chiropractor and acupuncturist, but as the severity grew, he turned to alcohol.

Then, in 2000, Grose went to the doctor for a sore throat and the doctor realized he was in pain. He referred Grose to a neurosurgeon. Grose entered pain management at a time when opioids were being marketed to doctors as a safe solution with little risk of addiction or overdose.

Over the next two decades, Grose had numerous surgeries, had metal plates installed in his back and neck, and developed arthritis of the spine and a host of other ailments that his many physicians have yet to find a way to heal.

His pain was near constant, and he was sometimes hit with sudden attacks so severe he wouldn't be able to get out of bed.

For years, his doctors experimented with different techniques to ease his pain. He tried electrical stimulation to block the pain signals from going to his brain. That worked for a while, but only at its highest voltage settings. He was prescribed oxycodone, an opioid, but it made him feel loopy, like he was drunk, and he didn't like it.

Finally, about six years ago, doctors found the dosage of fentanyl that made his pain bearable and allowed him to stay alert.

He continued to work in sales for Allstate Insurance for a few more years until the pain made it impossible for him to do his job.

When he didn't have to work and he had his pain medicine, Grose could live a good life. He ran errands while Debbie was at work. They would go out to the movies or to concerts. He could mow the lawn and walk his dog, Skipper.

Then, in September, a friend who was seeing the same pain doctor told Grose that he was being tapered off his medicine because of the new state regulations.

Grose didn't believe it. He'd been on the same prescription for more than six years. He figured the regulations would be focused on people with substance use disorder - the ones at greatest risk of overdose.

The prescription fentanyl patches didn't get Grose high, he said. They helped him live his life.

But in December, Grose went in for his regular appointment and his fears were confirmed.

His doctor planned to reduce his dosage of fentanyl and eventually stop prescribing it altogether. When he asked for an alternative, he said she told him there wasn't one. When he asked if he could go to another pain specialist, she told him that he wouldn't be able to find anyone to prescribe him opioids.

After all, she told him, the new regulations prohibited it.

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Dr. Mishka Terplan, who runs Virginia Commonwealth University's substance abuse treatment clinic, has seen hundreds of patients in the two years since the clinic opened. Many of them came in addicted to opioids and in search of medication to ease the withdrawal symptoms, which some describe as 100 times worse than the flu.

For the vast majority of his patients, Terplan assesses the person for a substance use disorder and offers the medication combined with counseling and peer support.

But a handful of patients who come to the clinic don't have a substance use disorder. They're people with severe pain from a chronic condition - like Grose - who have been dropped by their pain management specialists in the wake of the opioid epidemic. He calls them pain refugees.

They came to him, in many cases, because health care professionals at the clinics that had stopped giving them opioids thought that their insistence that they still needed the medication meant they must be addicted, and referred them to the recovery clinic instead.

But there's a difference between addiction and dependence, Terplan said. Dependence is a physiological response when the body becomes used to a substance. Addiction is when it becomes behavioral, leading people to use a substance compulsively, regardless of negative consequences.

Although he is not a pain management specialist, he said he won't send a patient in serious pain away, so he treats several "pain refugees" at the clinic.

The CDC's prescribing guidelines, Terplan said, were intended to encourage caution before starting a patient on opioids by exploring other pain management options first and beginning with low dosages. It's a method he calls "primary prevention," an effort to stop addiction before it begins.

"Primary prevention is way too late for this crisis," Terplan said.

He said decades of excessive opioid prescribing has already done its damage, as many of the people who started their addiction on prescription pills have turned to illicit fentanyl and heroin that is not controlled by prescription regulations or monitoring programs.

Now, Terplan said, the focus needs to be getting those who are already addicted access to naloxone, the overdose reversal drug that can save their lives, and into treatment and recovery.

It's true that opioids were irresponsibly overprescribed, he said, but the reaction to the overprescribing has gone too far the other way.

"The right level isn't zero," Terplan said. "Our reaction to the crisis is the mirror image of how we got there."

The Virginia Board of Medicine says prescribers have taken cues from news coverage of doctors being penalized and raided for overprescribing opioids, rather than reading the regulations themselves - which, they say, give great latitude to the prescribers, so long as they document their reasoning.

Still, an investigation by The Virginian-Pilot found that opioids had played a role in half of all revoked medical licenses in the state over the past decade, including for substance abuse and overprescribing.

Even as the Virginia Board of Medicine has acknowledged that misapplication of the regulations occurs, it stands by the regulations as they are written.

And for the first time in six years, there was a slight dip in the number of drug overdose deaths in Virginia in 2018, which state officials say is a sign that the regulatory efforts, along with expanded access to treatment, are making an impact.

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It has been a glimmer of hope for Dr. Omar Abubaker, an oral surgeon and professor at VCU's School of Dentistry.

As an oral surgeon, for many years, he didn't think twice about prescribing opioids for his surgery patients. In medical school, he was simply told how many milligrams to prescribe, with little explanation of the risks that come with the drug.

It wasn't until 2014, when his 21-year-old son, Adam, died of a heroin overdose, that Abubaker began to understand addiction as a disease and rethink his own prescribing practices. Adam started taking opioids he'd been prescribed for a shoulder injury and soon became addicted.

Abubaker believes that he and his fellow medical practitioners played a part in the opioid epidemic by overprescribing. Now, he always prescribes non-narcotic pain medication first, such as ibuprofen, and writes an opioid prescription only as a last resort.

In response to those like Grose and Terplan who say the regulations are cutting off people with chronic pain, Abubaker cautioned not to let those concerns overshadow the good regulations have done in protecting people from addiction.

"I think we have to find other ways to manage pain other than opioids," Abubaker said. "For those of us who lost children, they're not two comparable choices."

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Grose's uneaten yogurt sat on the kitchen table in between piles of folders full of his medical records that he'd assembled for his appointment. He didn't eat much anymore. The pain took away his appetite.

Debbie insisted on fixing him something though, and would often bring his food to his recliner on a tray, a stinging reminder to him of everything she has to do to take care of him. She frequently has to take off work to drive him to his many doctor appointments. The last time he drove himself, he was hit by a surge of debilitating pain and she had to come pick him up.

Ever since the doctor had reduced Grose's fentanyl prescription, he'd been conserving his medicine and his energy. If he sat in his chair all day and barely moved, it felt like the fentanyl patches would take longer to wear off. A pair of patches prescribed for two days could last as long as five days until the symptoms became unbearable and he'd have to put on a fresh pair.

He still had some pain pills left, too, which he kept in a cluster along with his other medications on the side table next to his chair. He takes the pills only when the severe attacks hit.

Five months before, when he'd learned that his pain management doctor was going to taper him off opioids, he'd felt hopeful. He thought maybe there would be some new alternative treatment that he could transition to that would be just as effective. It wasn't long before the fear set in.

As soon as his doses decreased, the pain increased, paired with withdrawal symptoms.

Grose started calling around to pain management doctors in the Norfolk and Virginia Beach areas, but time and time again heard the same response.

No, they weren't taking new patients. Besides, they're not prescribing opioids anymore.

One time, he managed to make an appointment with a specialist, only to be turned away at the office before seeing the doctor.

Grose said another doctor he saw wouldn't prescribe him any medication, but suggested he try to find a marijuana dealer.

Days turned into weeks, and then months, and still no doctor had agreed to take him on as a pain patient.

He passed the time sitting in the recliner that was wearing where his head rested even though he'd only bought it the year before, and watched episodes of "Law and Order."

Meanwhile, the backup medication he'd kept in reserve was running low. By the end of April, he figured he could manage for about another month.

In February, he'd made an appointment with an acclaimed pain specialist at Eastern Virginia Medical School, but the first opening wasn't until May 2.

With a litany of rejections and a dwindling supply of medicine, Grose held on to the upcoming appointment as his last chance.

If it didn't work this time, he didn't know what he was going to do.

**Side Effects: His opioid supply dwindling, Chesapeake man with chronic pain scrambles for relief**

Part two of a two-part series.

CHESAPEAKE - Charles Grose held his cane in front of him and used it as leverage to pull himself out of the recliner where he'd spent most of the past five months.

It was a quarter to 10, and time for him and his wife, Debbie, to leave for the doctor's appointment that they hoped would give him the relief he'd been searching for ever since his pain management doctor had told him she would be tapering him off the prescription fentanyl he'd been taking for six years.

"Don't forget your wallet," Debbie said. "And your files."

Grose checked his pocket, and Debbie doubled-checked the thick stack of paperwork to make sure they had everything. If they were missing anything, they might be sent away without seeing the doctor.

Grose had lost count of how many doctors he'd called, only to be told the same thing: No, they weren't taking new patients, and no, they wouldn't prescribe opioids.

After an influx of opioid prescribing led to a sharp increase in overdose deaths in recent years, creating a public health crisis, U.S. and state authorities have tried to rein in prescriptions for the drugs to stem the tide of fatalities.

But last month, the Centers for Disease Control and Prevention acknowledged that its guidelines have been misapplied in many cases - resulting in chronic pain patients being inappropriately tapered or cut off from their medicine.

Grose walked gingerly down his three front steps and headed slowly for the couple's Dodge pickup truck. Debbie went to get the newspaper from the driveway so she'd have something to read in the waiting room.

Twenty minutes later, they'd parked in a handicap spot and made their way into the Eastern Virginia Medical School Physical Medicine and Rehabilitation office.

Grose walked up to the receptionist and greeted her cheerily. The two fentanyl patches that Debbie had applied to his left arm earlier that day had eased his pain enough for him to muster a good mood.

Since he'd been conserving medication, on most days his pain - a result of two serious car accidents 35 years earlier - made him irritable and barely able to get up from his recliner.

"Got this stuff here for ya, all filled out," he said to the receptionist, handing her the lengthy acknowledgments that he'd had to sign, accepting that he'd have to submit to urine drug tests, random pill counts and a number of other measures to ensure he wasn't abusing his prescriptions.

"My neurosurgeon is right across the street," he told her, making conversation. "I've been operated on like five times at Norfolk General. Five or six, yeah."

The couple headed to the waiting area, where Debbie pulled out the newspaper. A headline on the front page declared that drug overdose deaths had gone down in 2018, though they still killed 1,484 people in Virginia. The drugs remain the leading cause of unnatural death in Virginia, but it was the first decline in six years.

Debbie shook her head.

She and her husband thought that all the attention on drug overdose deaths was what had prompted pain doctors to fear giving him the pain relief he needed.

Grose felt bad for the people suffering from opioid addiction, but he didn't understand why it had to affect him.

He thought the rules meant to prevent overdoses were pressuring him to look elsewhere to get drugs, the kind that weren't controlled by a doctor.

A staff member pushed open the swinging doors to the waiting room and called out a name.

"Did you say Charles? Yeah, that's me."

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In the U.S., opioid prescribing practices have fluctuated dramatically for centuries.

Doctors prescribed opioids and cocaine for common ailments like diarrhea and toothache until a sudden surge of heroin abuse and morphine dependence prompted federal regulations in 1914.

After that, doctors moved away from prescribing the drugs, according to "A Brief History of the Opioid Epidemic and Strategies for Pain Medicine," a scientific article published last year by several doctors from Harvard Medical School, Johns Hopkins Medical Center and Louisiana State University Health Sciences Center.

What followed were decades of what some call "opiophobia," when prescribing of opioids was shirked and stigmatized, including for cancer patients.

But in the 1990s, there was a movement by physicians to combat what they saw as undertreatment of pain. In 1995, the American Pain Society launched a campaign calling pain "the fifth vital sign," meaning doctors should ask patients about their pain at every visit, just like checking a pulse.

But unlike other vital signs, pain can't be measured objectively. National standards for pain management led some health care providers to believe they might be penalized if they didn't prescribe enough pain medicine.

At the same time, pharmaceutical companies amped up marketing that often was misleading for opioid medications, paying physicians to vouch that the drugs were a safe and humane option. Medical students were taught to rely on opioids for treatment of pain, and prescribing increased rapidly.

Prescriptions for OxyContin, a brand of opioid pain pill, jumped from 670,000 in 1997 to 6.2 million in 2002, according to the article.

Around that time, the first wave of overdose deaths began.

In 1999, at the same time prescriptions were increasing, the number of people dying from overdosing on prescription opioids began to inch up.

The second wave hit in 2010, when there was a sharp increase in heroin-related deaths as people turned to the illegal drug that's in the same family as painkillers.

And the third wave came in 2013, when powerful synthetic opioids, particularly illegally manufactured fentanyl, drove an even more dramatic increase in deaths.

The epidemic reached a record year in 2017, when 47,600 people in the U.S. died of an opioid overdose, according to the CDC. Fentanyl, the drug Grose relies on, is 100 times stronger than morphine and since 2015 has been the deadliest drug in Virginia.

In response to the escalating crisis, the CDC released opioid prescribing guidelines in March 2016 that advised primary care physicians to prescribe lower dosages, monitor patients closely and taper patients off the medication when possible.

The Virginia Board of Medicine relied on the guidelines when it developed its regulations in early 2017, which then went into effect in August 2018.

But even before the regulations went into effect, opioid prescribing began to drop.

Nationally, prescribing rates increased steadily starting in 2006, then peaked in 2012 with 255 million prescriptions before falling to the lowest rate in a decade in 2017.

In Virginia, there was a 30 percent decrease in the number of opioid doses dispensed between January 2017 and June 2018, from 29 million to 20 million, according to a report from the Prescription Monitoring Program, a state network designed to keep an eye on patients trying to score multiple prescriptions from different doctors and identify prescribers and dispensers giving out an inordinate amount of the drugs.

The Department of Medical Assistance Services, which runs the state's Medicaid program, lauds the fact that opioid prescriptions to Medicaid members were cut in half from 2012 to 2018.

At the same time, the agency is working to increase access to alternative pain management, such as topical anti-inflammatory medication and physical therapy, said Dr. Jennifer Lee, the agency's director.

But the agency doesn't have a system to track whether Medicaid patients feel that their pain is being adequately treated. The information, Lee said, may be reflected in patient surveys.

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Before 2013, most fentanyl-related deaths in the state were caused by prescription forms of the drug. But by the end of that year, toxicology testing found an increase in illicitly produced forms of fentanyl, according to the Virginia chief medical examiner's fatal drug overdose report.

By 2016, most of the 624 fentanyl deaths in Virginia - almost three times as many as the year before - were related to illicit forms of the drug. Heroin deaths also more than doubled from 2013 to 2016, from 213 to 448.

A research study published in the American Journal of Public Health in October concluded that policies to limit the supply of prescription opioids, such as prescribing guidelines, would likely result in an increase in overdose deaths over the next five years, as some people turn to illicit opioids and heroin in the absence of prescriptions.

But over 10 years, the study predicted the number of overdose deaths would likely go down as fewer people are exposed to the substances through a prescription.

"Reduced opioid prescribing could simultaneously reduce opioid addiction incidence while decreasing the quality of pain management for patients with legitimate need," the report stated.

It went on to say that policymakers "face difficult value judgments" when one policy intervention would avert some deaths but reduce quality of life for others or would increase quality of life for many and increase deaths for some.

On April 24, the CDC published a commentary in the New England Journal of Medicine warning practitioners not to misapply the guidelines that it had published in 2016.

The news release said the CDC is aiming to raise awareness of misapplications that could be putting patients like Grose at risk. Those missteps include reading the dosage recommendations as hard limits and abrupt tapering or sudden discontinuation of opioids.

In a letter to a citizen concerned about the tapering of chronic pain patients, the Virginia Board of Medicine explained that the state regulations do not limit dosages or require a reduction in opioid prescriptions. They do require the reasons for the treatment be documented in the patient's medical record.

"In essence, the prescriber has great latitude in prescribing for any patient," the letter read. "It just has to be done competently, safely and be well-documented."

The letter goes on to say that the board is aware that there are "ongoing misconceptions" about the regulations and that it is encouraging prescribers to read them rather than relying on word of mouth and media coverage of pain management practices being raided.

"Not understanding the regulations can be a disincentive to prescribe for chronic pain or maintain the treatment of patients in one's practice that have been stable, functional and without signs of abuse for years."

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Two hours after being called in to see the doctor, Grose and Debbie walked back through the swinging doors into the waiting room with muted smiles.

They walked straight to the receptionist's window to schedule Grose's next appointment.

It had almost been a dud.

Grose spent the first hour arguing with one of the doctors about prescribing guidelines. The doctor told him his doses were too high. Grose said he needed the relief.

"If you're in that bad pain, you're going to do something," Grose said. "Go out and buy drugs or get a gun and blow your brains out."

Scientific studies have shown a link between chronic pain and an increased risk of suicide.

Tired of doctors discounting his pain, Grose's temper rose and he nearly left the office in a huff.

But Debbie thought that if he calmed down, they could make their case.

After some time, Dr. Antonio Quidgley-Nevares, the chair of the Department of Physical Medicine and Rehabilitation at EVMS, came into the room and heard Grose out.

He said they could give him withdrawal medication to ease the symptoms he'd been fighting for the past five months and that they would refer him to another doctor on the campus who specializes in pain management implants and devices.

Grose asked what would happen if that didn't work.

Quidgley-Nevares said they would address it at that point.

It was far from a guarantee, but it was more than he'd gotten from any of the other doctors.

Grose said he wouldn't mind if the solution to his pain relief didn't involve opioids. All he wanted was to be able to live a life beyond his recliner.

If they could give him that, it would be enough.