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How the Global Pandemic Uncovered a Nursing Home System in Need of Repair and the Heroic Staff Fighting for Change

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To my beloved Brian for giving me the courage to be brave when faced with fear and to boldly speak for those that can't. I love you.

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FOREWORD

by Peter P. Patterson, M.D.,
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In late December 2019, cases of "Wuhan pneumonia" in China were reported to the Centers for Disease Control and Prevention (CDC) in Atlanta, Georgia, and major academic centers in the United States. On January 19, 2020, a thirty-two-year-old man traveled from Wuhan to his home in Snohomish County, Washington. He developed symptoms, was diagnosed with pneumonia, and hospitalized. He recovered ten days later. On February 28, 2020, a case of the "Wuhan pneumonia," now known as "Coronavirus disease 2019" (COVID-19), was identified in a female resident of a long-term care (LTC) facility in King County, Washington. Subsequent epidemiologic investigation identified eighty-one residents, thirty-four staff members, and fourteen visitors associated with that facility as having COVID-19. Of those 129 people, thirty-eight died, and Seattle became the epicenter for the first United States outbreak of COVID-19 in LTC facilities. Many such outbreaks followed as COVID-19 spread rapidly across the United States.

The COVID-19 pandemic caught everyone unaware. At first, no one knew how easily the virus transmitted, and, more importantly, how much viral spread could occur among asymptomatic residents and staff. As the nursing home industry became more knowledgeable, caregiving infection control practices had to change from week-to-week, even day-to-day. LTC facilities everywhere struggled to find supplies of personal protective equipment (PPE): masks, gowns, and face shields. With insufficient protection, doctors, nurses, and other caregiving staff contracted COVID-19. Many lost their lives. For caregivers, the pandemic became a national tragedy mixed with individual heroism.

Amid a rising chorus of public outrage, surveyors from federal and state regulatory agencies began an urgent campaign to inspect LTC facilities that had reported outbreaks. Surveyors could quickly identify infection control practices that were below the latest standard of care, even though those same practices may have been the proper procedures only a few weeks earlier. Under the strict regulatory process, surveyors could not offer helpful suggestions to surveyed facilities, only formal citations and fines. Their only tool was the hammer of fault-finding. Therefore, deficient care practices looked like nails that needed pounding. And pound away they did, issuing a stream of citations and fines to surveyed facilities that then had to take time away from care to respond with formal plans of correction. This cruel combination of regulatory burden on top of the pandemic burden created widespread stress and burnout in facility administration and staff.

Dr. Buffy Lloyd-Krejci did part of her epidemiological training at the CDC and was well-known to the LTC community. Her small consulting firm was frequently retained to assist facilities with their infection prevention and control programs. Called to action, Dr. Buffy quickly threw herself into the huge task of working with administrators and staff at LTC facilities across the United States.

What began as a journal to cope with overwhelming feelings quickly turned into a record of personal stories and research around the circumstances. *Broken: How the Global Pandemic Uncovered a Nursing Home System in Need of Repair and the Heroic Staff Fighting for Change* is a clarion call to every person in the United States who has, or who will have, a beloved family member or elder friend living in a nursing home, or a family member needing transitional care between a hospital stay and a return to home.

This book exposes many uncomfortable truths about the pandemic response and our LTC system. But light on these dark issues is the best catalyst for needed positive change. Dr. Lloyd-Krejci shines a light on those truths and invites readers to see for themselves the true sources of problems in the delivery of care for this vulnerable population. From there, anyone—resident or advocate, caregiver, administrator, policymaker, or legislator—can follow Dr. Lloyd-Krejci's lead and choose how they might participate in restoring the integrity of the post-acute care system.

How a society conducts itself in a disaster such as a pandemic is a measure of its overall health and well-being. Dr. Lloyd-Krejci is calling us to share her commitment to creating the needed political alliances and high-level agreements between all of us who are stakeholders in this great task of caring for our vulnerable community members. Awakening to this call is crucial to the future of our communities of caregivers, healers, and especially our elders.

INTRODUCTION

"I'll never go into a nursing home."

Most of us have said this, and many of us believe it. But the truth is that staying out of a care facility simply may not be an option, once we reach an age or circumstance that incapacitates us.

If you have a loved one in the care of a nursing home, you already know this. But you may not know the true nature of the environment where your family member now lives, or what you can do to advocate change—not only for your loved one, but for those who follow. What will it take for Americans to feel comfortable with long-term care?

It's a fair question. In the United States, nearly sixteen thousand nursing homes provide care to over four million people every year.[1] As the baby boomer generation (those born between 1946 through 1964) ages, more of us will require long-term care services. In fact, it is estimated that eighty-eight million Americans will need long-term care services in 2050; this is an 84 percent increase from the forty-eight million that required services in 2015.[2]

Before the COVID-19 pandemic, long-term care facilities, commonly known as nursing homes, did not have a strong focus on infection control practices. It was no surprise that the Centers for Disease Control and Prevention (CDC) estimated that nearly three million severe infections led to 380,000 deaths each year.[3] That's more than a thousand deaths per day. While these statistics are scary, the most maddening aspect of these numbers is the estimated percentage of preventable infections. Conservative estimates say 40 percent, while some suggest up to 70 percent of infections, are preventable. Even on the low end, *we are talking about saving four hundred lives every day*.[4] The consequences of not having infection control as a priority is dire.

These numbers and other equally startling information felt to me like a personal call to action. In the spring of 2018, I left my cushy corporate job with its health insurance and 401(k) and dedicated myself full-time to bringing awareness of this preventable problem. I reached out to hundreds of nursing homes, corporate leaders, and federal decision-makers including the Centers for Medicare and Medicaid Services (CMS), the primary payer and regulatory licensing agency for long-term care services, and told them, "There's a problem here, and I can help you with it."

It felt as though we were on the Titanic—the iceberg, straight ahead—and few cared what I had to say. Thinking perhaps that spreading the message alone was the problem, my husband quit his job and joined me in my outreach effort. Believing in our cause so deeply and recognizing the magnitude of the problem, we innocently thought that facilities would jump to get on board as long as we arrived with a solution to solving the problem of infection control.

It turned out we were mistaken. After a year of making hundreds of phone calls, sending thousands of emails, conducting dozens of free webinars, and presenting at conferences across the country, only seven nursing

homes hired us to help them improve their infection control program. The government response wasn't much better. I presented a detailed plan to the long-term care CMS team on how to reduce resident harms and deaths due to infectious diseases with no follow-up; no action steps were taken to move forward with the plan.

So why do I keep going? Why bring this issue forward into 2022 and beyond? The time is long past due to provide safe and effective care to our long-term care residents and a safe environment for the dedicated staff. As an expert in long-term care infection prevention and control, I have supported hundreds of nursing homes across the country and have witnessed the devasting consequences of COVID-19.

The stories have all been the same: lack of support, lack of understanding, and a governmental approach that includes a system of bullying, fines, and punishment that dictate every change in this healthcare setting. Representatives of Doctors Without Borders, nursing home administrators, academic researchers, national and international advocacy groups, state licensing agencies, healthcare workers, and patients all have a different story to tell.

Given the punitive regulatory environment of this industry, I have changed many of the names of the individuals in these pages to protect their identities. But you'll hear them describe the challenges in nursing homes prior to the COVID-19 pandemic, alongside my own personal experience with grandparents who lived out their final days in a nursing home. I'll describe how academic researchers have published data for years about the infection control problems in nursing homes and the interventions that began prior to the pandemic.

I'll also describe the early response from nursing homes to COVID-19 and how the federal government chose to respond to nursing homes with a punitive strategy, rather than one that was collaborative and supportive.

Finally, I'll describe how we can use this dark season to transform the long-term care industry into a supportive healthcare system that provides safer, more reliable care for our loved ones.

If you have a loved one now in the care of a nursing or rehabilitation home, this book will equip you to understand the true nature of that environment and what you can do to advocate change when necessary. Your actions will have a lasting impact! What will it take for us as citizens and community members to feel comfortable with long-term care? We should not have to cringe and say, "I'll never go into a nursing home," because that may not be the reality.

Now is the time to create change and to have our voices heard. Together, we can assist in shifting punitive strategies of control to a culture of collaboration and support, a culture that provides the best opportunity to give residents the care they deserve—and the working conditions expert caregivers are worthy of receiving.

CHAPTER 1

A HOUSE ON FIRE

"It isn't that they can't see the solution. It's that they can't see the problem. They can't see the problem if they are looking in the wrong place. They can't see the problem if they have blinders on—for 'none are so blind as those that will not see.'"
—Gilbert K. Chesterton

November 25, 2018, Baltimore, MD

My heart is racing.

I can't get to my computer fast enough. I need to ring an alarm bell; let government officials—the world!—know about the atrocities I've discovered in a local nursing home. I know that, once the right people know what's going on, they'll race to remedy the situation and help the facility.

I'm here in Baltimore as a consultant for a public health organization. Concerned about the care her ninety-four-year-old aunt Nannie was receiving, Crystal, the organization's administrative assistant has asked me to visit the Patuxent Health and Rehabilitation Center, where Nannie lives. Crystal knew of my expertise in infection prevention and control (IPC) in nursing homes and trusted my opinion of her aunt's current care home.

We'd headed for the nursing home on a cold autumn day—something I, a longtime Phoenix resident, wasn't accustomed to. We planned to attend a family council meeting, a perfect opportunity to visit and hear the concerns of family members of the facility's residents. We arrived after a forty-five-minute drive; it was after-hours, but the doors were still open for the meeting.

The smell of urine smacked me in the face as soon as I walked in the door.

Twenty or thirty years ago, a person might have expected this rank odor in any nursing home, but it's much less common today. I introduced myself to a tall blonde seated at the reception desk, who surprised me with the news that she was the nursing home's administrator.

Didn't she notice the smell?

I explained I was there to support my friend Crystal, that I was an infection control expert, and would participate in the meeting. As I handed her my card, I assumed she'd feel delighted to take advantage of my knowledge. I really thought she would welcome outside support. Little did I know!

The meeting room was full. Among those there to represent their loved ones was Crystal's ninety-two-year-old mother Violet, seated in a wheelchair. She traveled across town on two buses every other day to visit her ninety-four-year-old sister "Nannie."

Crystal explained to the group that I was there to listen, learn, and hopefully help. The meeting started with a lot of legal jargon about recent state legislative actions, but I snapped to full attention when talk turned

to the recent outbreak of scabies, a highly contagious infection that causes itching from mites that live beneath the skin. The council members, suspecting a cover-up, complained that this "five-star" facility hadn't notified the families of this outbreak. They argued that it was the mother of a resident and the family council president, Twila Bridges, who'd contacted the state's Office of Health Care Quality (OHCQ) and reported an urgent need for help. It took a patient advocate to ensure that every resident was treated for the scabies. Sadly, for one resident, it was too late. He'd scratched himself badly enough that his skin became infected. He developed sepsis (a bloodstream infection) and died. I sat in shock as I heard the description of this tragedy about a human life that could have easily been spared with the early identification and treatment of the infection.

As the meeting continued, council members reported other potentially fatal infectious outbreaks such as *Klebsiella pneumonia*, *Clostridioides difficile*, and influenza. One daughter told of how her mother continued to get urinary tract infections (UTIs). Because she was also immunocompromised, the woman worried that the condition would lead to sepsis and cause her mother's death.

I knew the dangers of sepsis, a life-threatening condition with an associated mortality rate of up to 41.1 percent. Sepsis secondary to a UTI accounts for nearly 25 percent of all sepsis cases. The urinary tract is the second most common infection site, accounting for approximately 20 percent to 40 percent of all severe cases of sepsis in patients.[1] Given the high incidence and severity of sepsis, early recognition and appropriate management of UTIs play a vital role in preventing the disease progression to urosepsis.

I was frantically taking notes, trying not to miss one word. What could I do now? Who could help them? The family members mentioned they'd already contacted their Ombudsman, appointed by the facility to record complaints, and even called on Maryland state senator Jim Rosapepe for

help (he'd eventually assist in making changes). The families had taken these actions yet had been largely ignored until this point.

Crystal and I needed to leave the meeting to visit Nannie while she was still awake. As we left, I made a sincere promise to the group to do everything I could to help. The frustration in one family member's outburst startled me.

"That's what they all say! You're not going to help. Nobody ever helps!"

Others stepped in to quiet her, to keep her from offending me, but I felt her pain. Her cries had gone unanswered. To her, I was just another voice promising to make a change. I let her vent. When she was done, I reassured her that I'd recently quit my job expressly to assist in solving this problem. I knew she didn't believe me. Why would she? So far, no one had supported her. I left the meeting feeling heartbroken.

Walking down the hall beside Crystal, I noticed there were no hand sanitizing dispensers in the hallway. How did anyone practice hand hygiene? There were none in Nannie's room, either. Two nurses came in to provide care to Nannie's roommate, neither washed their hands before or after providing care.

"They never do," Crystal told me. There was a sink in the restroom—not a suitable place to practice consistent hand hygiene—but it went unused. No wonder these infectious outbreaks were occurring; they weren't implementing basic infection-control practices. How was the nursing home staff passing over something so fundamental?

I made an instant connection with Nannie, a strong, feisty African American woman. She was in continual pain, though; the arthritis in her hip was unbearable. Crystal and I gave her a back and hip rub to ease the pain. Crystal told her that I was there "to help."

Nannie looked at me with conviction and said, "Good. We need it." She then offered me a piece of her much-valued bubble gum, a simple yet meaningful gesture, that solidified our new friendship.

Back in my hotel room, I opened my laptop. *I will sound the alarm*, I thought as I began an email to the leaders of the Centers for Medicare and Medicaid Services (CMS). I described the outbreaks at Nannie's facility, the lack of help from the state and other advocates. I pled with them to make this a priority, told them I was willing to fight this battle one nursing home at a time. With their help, their influence, their power, I typed, we could make an immense difference and decrease the risk of harm and death due to infections. Based on my studies, I explained, this situation was not an isolated event. It was a countrywide, systemic issue.

Exhausted, I crawled into bed. *There*, I thought as I drifted into a fitful sleep. *I've started the ball rolling. Once the powers that be are aware of what I've seen tonight, they'll jump in and we'll start making a difference*.

I had no way of knowing how mistaken I was.

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