# The Forgotten Responders: The Ongoing Impact of 9/11 on the Ground Zero Recovery Workers

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## Abbreviations:

9/11: September 11, 2001 terrorist attacks EMT: emergency medical technician FDNY: Fire Department New York GERD: gastro-esophageal reflux disease NYPD: New York Police Department WTC: World Trade Center

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# Abstract

In the years following the September 11, 2001 terrorist attacks (9/11; New York USA), emergency first responders began experiencing a range of physical health and psychosocial impacts. Publications documenting these tended to focus on firefighters, while emerging reports are starting to focus on other first responders, including paramedics, emergency medical technicians (EMTs), and police. The objective of this research was to explore the long-term impact on another important group of 9/11 responders, the non-emergency recovery workers who responded to the World Trade Center (WTC) site of the 9/11 terrorist attacks. In the 16 years following 9/11, Ground Zero recovery workers have been plagued by a range of long-term physical impacts, including musculoskeletal injuries, repetitive motion injuries, gait deterioration, and respiratory disorders. Psychosocial issues include posttraumatic stress disorder, anxiety, depression, insomnia, support system fatigue, and addictive and risk-taking behaviors. These findings go some way to filling the current gap in the understanding on the long-term impact of 9/11 and to provide an important testimony of the "forgotten responders" – the Ground Zero recovery workers.

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# September 11, 2001

The September 11, 2001 terrorist attacks (9/11) on the World Trade Center (WTC) in New York City - otherwise known as 9/11 - resulted in the largest concentrated emergency service response in United States history.

At least 100 ambulances raced to the scene, setting up triage centers and beginning to treat and transport people. More than 2,000 police officers from the New York Police Department (NYPD) and Port Authority secured the area and began to evacuate survivors. But the response was, first and foremost, a Fire Department New York (FDNY) operation involving 214 FDNY units.<sup>1</sup>

But this summary only partly conveys the true scale and complexity of the overall response to 9/11. Off-duty firefighters, paramedics, emergency medical technicians (EMTs), and police officers – at times, entire companies – self-dispatched to the site without orders. In the days, weeks, and months that followed, tens of thousands of non-emergency responders joined forces with the emergency first responders to mount an unprecedented response to one of the most-covered media events of all time.

After 16 years, the images are still difficult to view. These attacks, and the global reaction to them, have profoundly shaped the world today. So, it remains important to understand the long-term impact on the responders who put themselves at risk to try and bring closure to the families of the victims.

# The "Forgotten Responders"

For most people, the story of 9/11 ends with the collapse of the towers. The recovery operation that lasted for approximately eight months is generally nothing more than a footnote or a few scenes of footage tacked on to the end of 9/11 media that usually surfaces around each anniversary.

But if any of the footage of the aftermath at Ground Zero is watched, it will no doubt show thousands of people climbing on top of the pile, carefully looking for victims, while also clearing the immense pile of smoldering debris that was all that remained of the famous twin towers. Has anyone ever wondered who all of those people were? New York City didn't have enough emergency rescue personnel to continually man the 12-hour search shifts – no city does. So, who were they?

They were regular people. Ironworkers, sanitation workers, engineers, heavy equipment operators, truck drivers, and construction workers who were tasked with the physical work of cleaning up the wreckage of what remained of the WTC towers. Most of them volunteered from all over the United States, spending lengthy periods of time away from their families to work on top of the mountain of still-burning rubble, breathing in toxic smoke, and risking their own health on a daily basis in the hopes of doing some good.

John Feal, a foreman with a private demolition company, was working on a job site about an hour upstate of New York City when his crew got the news that a plane had struck the North Tower. After reports came in minutes later that the South Tower had also been hit, John gave the order to the men on site to go home. John, however, packed up and headed straight to New York City with whoever wanted to come along. They were motivated by the thought of people buried under the rubble, and they knew they could help get them out.

When John arrived at Ground Zero, he realized that he was one of hundreds, if not thousands of volunteers to self-deploy to the WTC site. Most had no clear idea about what they were going to contribute to the overwhelming task at hand, but many had come to help with the demolition and excavation that was going to be needed. The immediate goal was finding any survivors under the 1.8 million tons of steel, concrete, and plaster that made up the pile.

In those early hours, everyone at the site was convinced that they would find survivors. Surely, there were voids within the rubble where people were waiting to be rescued. There had to be people who had survived the collapse of the buildings, only to be trapped somewhere below the debris. Within those first 48 hours at Ground Zero, the thousands of emergency responders joined forces with the tens of thousands of non-emergency recovery workers like John to try and find those buried below.

Below the pile – as Ground Zero had been dubbed by the responders and recovery workers – subterranean fires continued burning for around 100 days, a hostile pile of heat, acrid smoke, and anguish. Despite the obvious danger – no volunteers were turned away, the need for sheer numbers was immediate and dire.

But as the days wore on, and with hope of finding anyone else alive beginning to fade, the initial search and rescue activities changed to debris removal and remains management. The "bucket brigades" of emergency and non-emergency responders working together could be seen lining the surface of the pile like lines of ants. A human hand was found, placed in a bucket, and moved along the convoy line until it was sent to the temporary morgue on site. A lower leg with a high heel shoe still attached. A pinky finger. A piece of bone, a fragment of flesh, a firefighter's jacket with no body inside. Legend has it that a whole human heart was found on the subway tracks deep below the WTC site.

## The Dangers of Ground Zero

August 2018

John Feal realized early the importance of implementing some form of coordination and control at the scene. People who didn't know what they were doing were climbing all over an unstable, smoldering pile of debris. It was an accident waiting to happen. Taking on a role that he was familiar with as foreman, John set about finding qualified people among the sea of well-intentioned volunteers and matched them with appropriate tasks.

And that's how it was in those chaotic early days. He would train someone on a certain piece of heavy machinery and then move on to the next person and the next task that needed to be addressed. There was no time to worry about who had what certification - the experienced people had to hope they could share enough on-the-job training to the newbies to bring them up to speed.<sup>2</sup> It was quickly becoming one of the largest volunteer movements the United States had ever seen.

Mountains of work gloves and piles of other equipment were donated. Emergency responders and recovery workers were fed by food sent in from all over the country. Chiropractors and physiotherapists volunteered their time to massage the tired and aching responders. Mental health practitioners and religious representatives provided responders with the opportunity to talk and reflect on the devastation that they were in the midst of. People sent in blankets which responders rested under when they came in from their 12-hour shifts on the pile. New Yorkers lined the perimeter of the Ground Zero site, cheering and yelling "thank you" to the responders as they sought a brief moment of refuge from the hell of the mass-burial site.

Then there were the family members of the victims, straining over the barriers that had been put in place around the site, calling out to responders and holding up pictures of their loved ones, asking if they had seen them. As the days turned into weeks, these families knew that their loved one wasn't coming home. But still they came, still they showed their photos, always with that same look in their eyes. Other people would offer gift bags, or just generally offer their support and gratitude.

The emergency responders and recovery workers usually worked 12-hour shifts with very few breaks, quickly eating when they could before moving on from one project to the next. Some workers set up temporary shelter or found places to sleep nearby in the city. Some rested in St. Paul's Chapel, which sits directly across the street from the WTC site. After the terrorist attacks, St. Paul's suffered no physical damage. The NYPD turned a nearby blownout Burger King into a temporary headquarters. Thousands more rested wherever they could – on cots lining the perimeter of the site, some even sleeping directly on top of the toxic pile of debris.

Only 20 survivors were pulled out from the rubble after the towers collapsed and none were found after the second day. And yet, thousands of volunteers like John worked side-by-side with the emergency first responders searching, hour after hour, day after day, in hopes that somebody had defied the odds. He said that one thing he was never going to forget was seeing grown men at Ground Zero weeping as they slowly realized the chances of finding anyone alive were quickly dwindling to zero.<sup>2</sup>

There is something else that isn't apparent in the footage of Ground Zero. Thousands of responders can be seen climbing over the mountain of debris without realizing that what these responders were precariously perched on top of was a pile of loose debris ready to shift and collapse at a moment's notice.

And it was a dangerous landscape to be working in. Aside from the long-term danger of breathing in the toxic dust that polluted the air and covered every surface, there was the risk of immediate injury from walking over the moving, smoldering pile of debris. The whole time John and the rest of the responders were working, it was with the knowledge that the ground could give way beneath them at any moment. Each step came with the knowledge that they could be plunged into the dark, burning hell below Ground Zero. The danger finally caught up with John on September 17th. He was helping to load a truck full of debris, something he had done dozens of times already. Before he knew it, around eight tons of steel was falling towards him. He had to leap out of the way, and it was probably just incredible luck that he wasn't killed. After recovering from the shock of the incident, John noticed a shooting pain coming from the end of his leg. His foot was severed entirely and blood was spurting several feet into the air.

A fellow responder made a makeshift tourniquet to help cut off the bleeding, and John was rushed to hospital. After months in the hospital undergoing various reconstructive surgeries and almost dying of gangrene, he lost around one-half of his foot. Much more time spent in physical therapy has enabled him to walk with only a slight limp now. It was only later that he would realize how close he had come to being the first fatality of the WTC clean-up:

"As soon as they amputated it, I probably didn't talk to anybody for about four days," he recalls. "I just counted ceiling tiles. I just went into complete shutdown."<sup>3</sup>

Over the next five years, John underwent more surgeries on both feet. He couldn't work because of his injury. And, because of when he got hurt, his application for financial help was denied. Only people who got hurt within 96 hours of 9/11 were eligible to receive money from the first victims' compensation fund set up by Congress. John was hurt almost 120 hours after the attacks.

That timing is what has transformed his life. An Army veteran, he refused to accept the terms the government laid down. And he has since worked to change them – setting up the FealGood Foundation (Nesconset, New York USA) – to help anyone affected by 9/11 get health insurance and other benefits.<sup>3</sup>

# The Physical and Psychosocial Toll

Ground Zero recovery workers regularly sustained musculoskeletal injuries. Hundreds had repetitive motion injuries, like carpal tunnel syndrome. Responders were treated for fall injuries, back injuries, lifting injuries, knee and ankle injuries, abrasions, burns, sprains, and fractures. Responders climbed through the remnants of the twin towers, balanced on beams to search for bodies and perform cleanup, and all the while had burning debris falling on them, so the injuries were severe.

Many of the responders originally seen with serious hip and knee injuries are now demonstrating gait deterioration and require surgery to replace the affected joint. It isn't known yet all of the impacts the trauma of 9/11 will continue to have on the musculoskeletal system of responders. Many are being treated for asthma and use steroids, which are known to wreak havoc on bones. Responders can have so much bone disease that they fracture bones when they cough, and they cough a lot because of the asthma. It also isn't yet known the potential harmful impact that all of the medications used by the responders for other 9/11related conditions may have on the musculoskeletal system.<sup>4</sup>

Chronic gastro-esophageal reflux disease (GERD) is a common condition seen in the Ground Zero recovery workers; GERD is a digestive disorder in which stomach acid travels back up into the esophagus. It's not certain which particles or fumes in the dust cloud contributed to this condition, but it's clearly related. Chronic reflux can cause precancerous changes in the lining of the lower esophagus, known as Barrett's Oesophagus. Although the progression of Barrett's Oesophagus into cancer is very low, many responders are worried about it. In some responders, GERD has evolved into a form of intractable reflux. It may not respond to any medications and quality of life can be very poor because of constant symptoms. In addition, a lot of responders are at an age where you wouldn't expect them to be having such severe reflux symptoms. While reflux is a common problem, the difference is that some of the 9/11 responders appear to be less responsive to the medical therapies.<sup>4</sup>

In the next five to ten years, a continued progression of gastrointestinal disease could be seen that leads to elevated rates of colon polyps or colon cancers as compared to the general population.

Like the emergency first responders, the Ground Zero recovery workers commonly have mood disorders, which include major depressive disorder, mild and moderate depression, anxiety, panic disorder, and generalized anxiety disorder. Responders have experienced other physical symptoms such as decreased appetite, abnormal sleep patterns, problems with their memory, and difficulty concentrating. Something particular to this population is that they have demonstrated a tremendous amount of avoidance. They don't necessarily have memory impairment but are using avoidance as a psychological way of defending and protecting themselves from things that were painful.<sup>4</sup>

More frequently now, adjustment disorders are also being seen, where responders had been functioning with some underlying anxiety but are now facing major life changes—like retirement, developing cancer, chronic medical illness, or other major tragedy —that pushes them over the edge. For the general public, retirement is usually something to look forward to, but for many Ground Zero recovery workers, work was the stabilizing factor in their life. It allowed them to escape from their worries and was truly part of their identity. That identity helped them continue to be strong and powerful, but when that's taken away, they begin to feel weak and vulnerable. That weakness is actually what becomes anxiety invoking.<sup>4</sup>

Incredibly, in the eight months that thousands of responders worked at the Ground Zero site, no one was killed. But over one thousand first responders have died since.

Over 7,000 9/11 first responders and recovery workers are registered with the World Trade Center Health Program (Washington, DC USA), and over 2,500 have had to retire on disability due to causes linked to 9/11.<sup>5</sup> Doctors with the World Trade Center Health Program, which was created by the federal government in the aftermath of the attacks, have linked nearly 70 types of cancer to Ground Zero – cancers that are rare, aggressive, and particularly hard to treat.<sup>6</sup> They have also identified a 15% higher cancer rate among 9/11 responders than those who were not exposed to the toxic cloud that bellowed out from Ground Zero.<sup>7</sup>

## The Toxic Dust

The main reason for all of these deaths and illness? The toxic dust cloud that consumed Ground Zero and lower Manhattan. Smoke, dust, ash.

Four months after the disaster, there were reports that one-half of the workers at Ground Zero, perhaps the most hazardous work site in the nation, were not wearing respirators. From the very beginning of the operation until months later, many observers pointed to poor compliance with the requirement to use respirators as one of the most serious safety and health shortcomings at the WTC site. The National Institute of Environmental Health Sciences (NIEHS; Research Triangle Park, North Carolina USA) directed attention to this problem in its October 6, 2001 report on the early response to the disaster, noting: "Respiratory protection is rare."<sup>8</sup>

Respirator use by heavy-equipment operators was never above 50%, and at times, dipped to 20% despite intense education efforts. On top of the long hours and discomfort of wearing the devices, poor role models abounded at Ground Zero. Supervisory personnel from many responding organizations on site regularly entered the restricted zone without respiratory protection: "Respirators were worn much like loose neckties, hanging below the neck."<sup>8</sup>

Complicating matters was that many of the recovery workers were allegedly immigrants or undocumented aliens, hired to clean up the buildings near Ground Zero; these workers faced the risk of exposure to hazards with very limited protection and almost nonexistent support infrastructure.

Further compounding the illness and long-term impact is the ongoing financial hardship faced by so many of the Ground Zero recovery workers and their families, who have been left with not only the physical impact of volunteering their time, but also the mounting medical bills and the grief over the continued death toll of 9/11.

If the responders didn't have health insurance, they were faced with the prospect of trying to find tens of thousands of dollars to pay their medical bills. They can't write "But I was at Ground Zero!" on a six-figure hospital bill and expect them to apologize and wipe out their tab.<sup>2</sup>

When the clean-up was finished in May 2002, the Ground Zero recovery workers had moved 108,000 truckloads of debris – around 1.8 million tons of material. The complexity of the activity performed at one site—rescue, recovery, demolition, and construction—is unprecedented. Many key recovery functions had significant environmental, safety, and public health implications for the responders involved. The earliest responders to the 9/11 terrorist attacks were trained fire and police personnel. Unfortunately, many other responders, such as construction, demolition, ironworkers, electricians, volunteers, and cleaners, had never been trained or advised to use proper personal protective equipment, nor educated about the potential hazards at Ground Zero.

Respiratory protection was rare and responders were often observed in the smoke plume emanating from the pile without hard hats, eyewear, or respirators. Oftentimes, responders did not decontaminate after leaving the site. The hand/face and boot wash stations did not appear to be used by most of the workers.

During the September 22-26, 2001 period, an increase in worker protection was observed, notably respiratory protection. Hosing down the vehicles leaving the site finally began. There was no evidence that any safety and health programs were operating at the site. Various support personnel, workers, and government officials confirmed the lack of an operating safety and health program.<sup>9</sup> The absence of site-specific hazard training and a uniform health and safety plan greatly increased the vulnerability of those with less experience with hazardous work or rescue and recovery.

- Flood J. First responses. A race to the scene, and then—chaos. http://nymag.com/ news/9-11/10th-anniversary/first-responses/. Published August 27, 2011. Accessed August 21, 2017.
- Cabe I, Feal J. Five things I saw as a 9/11 first responder. http://www.cracked.com/ personal-experiences-1418-5-things-i-saw-as-911-first-responder.html. Published September 11, 2014. Accessed July 12, 2017.
- Davis LE. First responder fights back after losing foot to 9/11 accident. https://www. yahoo.com/news/first-responder-fights-back-afterlosing-foot-to-9-11-accident.html. Published August 17, 2011. Accessed July 19, 2017.

### Limitations

One of the key limitations of this review paper is the anecdotal nature of much of the information that is available on the longterm and ongoing impact of 9/11 on the recovery workers. The compelling nature of personal testimony makes it one of the most seductive sources of information and it can be tempting to draw conclusions from such anecdotes. However, it is important to note that anecdotal evidence is usually based on individual experiences or observations, as distinct from probabilistic evidence that gives estimates of how likely something is to occur based on experience with large numbers of people. The primary weakness of anecdotes as evidence is that they are not controlled. This opens them up to many hidden variables that could potentially affect the results. Therefore, any reliable assumptions cannot be made about which variable was responsible for any one outcome. Despite these shortcomings, anecdotal evidence has its place in ensuring that important stories are told, particularly when there is a need to consider both the objective and the subjective. The danger in dismissing the anecdotal is that science gets too far removed from the actual experience of life, losing sight of the fact that statistics and high-level evidence won't always give the "full story."

While much of the evidence on the ongoing impact of 9/11 on recovery workers is largely anecdotal, WTC-related health effects have been reported in a number of published research studies which highlight an increased incidence of health effects in the respiratory and gastro-esophageal tracts, low birth weight and birth defects in children exposed in-utero,<sup>10,11</sup> posttraumatic stress disorders,<sup>12-17</sup> as well as a growing concern about excess cancer incidence.

When cancer rates for emergency first responders are compared to the general United States population, cancer rates are around 10% higher for the 15,700 firefighters and Emergency Medical Services workers/EMTs whose health is being tracked by World Trade Center Health Program. New research confirms that this toxic cocktail caused heightened rates of cancer. When compared to pre–9/11 data, the cancer rates range from 19% to 30% higher for firefighters after the data are adjusted for age, exposure, and other factors.<sup>5</sup> However, much of this published literature is focused on the emergency first responders and further research is required to determine the long-term impact amongst recovery workers and how morbidity and mortality rates compare with those of the general population.

### Conclusion

A web of failures has ultimately resulted in mass loss of life and ongoing illness and disability of the 9/11 Ground Zero recovery workers – people who volunteered their time to help respond to the nation's most devastating terrorist attacks. And unfortunately, the death toll and incidence of illness continues to rise, with responders dying on an almost weekly basis, some 16 years after the attacks.

- Lynch L. Health and hardship: stories from 9/11's unsung heroes. http://nycosh.org/ wpcontent/uploads/2015/09/NYCOSH\_9\_11\_Responder\_Report\_HealthAnd-Hardsh ip.pdf. Published September 2015. Accessed July 25, 2017.
- McGrath Goodman L. 9/11's second wave: cancer and other diseases linked to the 2001 attacks are surging. http://www.newsweek.com/2016/09/16/9-11-death-tollrising-496214.html. Published July 9, 2016. Accessed August 9, 2017.
- Solan S, Wallenstein S, Shapiro M, et al. Cancer incidence in World Trade Center rescue and recovery workers, 2001 – 2008. *Environ Health Perspect*. 2013;121(6):699-705.

References

- Fire Department, City of New York: Bureau of Health Services WTC Medical Monitoring and Treatment Program. World Trade Center Health Impacts on FDNY Rescue Workers. http://home2.nyc.gov/html/fdny/html/publications/wtc\_assess ments/2007/w tc\_2007.shtml. Accessed February 19, 2016.
- Nash J. Cleaning up after 9/11: respirators, power, and politics. http://www.ehstoday. com/ppe/respirators/ehs\_imp\_35479. Published May 28, 2002. Accessed August 1, 2017.
- Crane MA, Levy-Carrick MC, Crowley L, et al. The response to September: a disaster case study. *Ann Glob Health*. 2014;80(4):320-331.
- Berkowitz GS, Wolff MS, Janevic TM, et al. The World Trade Center disaster and intrauterine growth restriction. JAMA. 2003;290(5):595-596.
- Lederman SA, Rauh V, Weiss L, et al. The effects of the World Trade Center event on birth outcomes among term deliveries at three lower Manhattan hospitals. *Environ Health Perspect*. 2004;112(17):1772-1778.
- Fairbrother G, Stuber J, Galea S, et al. Posttraumatic stress reactions in New York City children after the September 11, 2001, terrorist attacks. *Ambul Pediatr.* 2003;3(6):304-311.

- Boscarino JA, Galea S, Ahern J, et al. Psychotic medication use among Manhattan residents following the World Trade Center disaster. J Traum Stress. 2003;16(3):301-306.
- Galea S, Vlahov D, Resnick H, et al. Trends of probable post-traumatic stress disorder in New York City after the September 11 terrorist attacks. *Amer J Epidemiol*. 2003;158 (6):514-524.
- Brackbill RM, Thorpe L, DiGrande L, et al. Surveillance for World Trade Center disaster health effects among survivors of collapsed and damaged buildings. *MMWR Surveill Summ.* 2006;55(2):1-18.
- Luft BJ, Schecter C, Kotov R, et al. Exposure, probable PTSD, and lower respiratory illness among World Trade Center rescue, recovery, and clean-up workers. *Psychol Med.* 2012;42(5):1069-1079.
- Friedman SM, Farfel MR, Maslow CB, et al. Comorbid persistent lower respiratory symptoms and posttraumatic stress disorder 5-6 years post-9/11 in responders enrolled in the World Trade Center Health Registry. *Am J Ind Med.* 2013;56(11):1251-1261.