Prolonged grief disorder: 5-15% of bereaved people experience chronic mourning. What does that mean and how might it impact your health?

In September 2020, my father died. I was sad for a while and had trouble sleeping, but I managed to keep working and taking care of my young daughter. Eventually, the good memories began to overpower the bad, and I started to feel like myself again. This is what grief looks like for most people: intense feelings that gradually dissipate over the course of a few months.

But it's not what I experienced when my mother died 15 years ago. She had Lou Gehrig's disease, and her death permeated every aspect of my life for years. I felt like a ghost and had to keep reminding myself that I was still alive, that I hadn't died with her. I had no idea who I was — or how to live my life — without her, and cried constantly. This went on for years.

Every human being will experience grief at some point in their lives — it's a fundamental human experience. "I think it's important to underscore that people are equipped to grieve, and for the most part people do it OK," says Anthony Mancini, a psychological researcher at Pace University in Pleasantville, New York.

But some mourners are not OK. When my mother died, I developed what's known as prolonged grief disorder (PGD), a different sort of grief that psychologists are just beginning to acknowledge and understand. People with PGD — sometimes called "complicated grief" — aren't just struggling to "get over it." They have a defined disorder, one recently added to "psychiatry's bible," the Diagnostic and Statistical Manual of Mental Disorders (DSM).

Characteristic features include an inability to shake thoughts of their loss, leaving them in a state of chronic mourning, which can severely affect their ability to function — to work, parent or be a partner — and puts them at risk of suicide. Emerging research suggests that they may also exhibit unique patterns of brain activity. They don't respond to antidepressant medications or therapy directed at normal grief but can get some relief from newer treatments tailored specifically to PGD.

Researchers estimate that between 5 percent and 15 percent of bereaved people will develop PGD; roughly 2 percent to 3 percent of the world is experiencing PGD at any given time. But that's when the world is not living through a pandemic that has caused more than 6 million deaths so far — and, as a result, more cases of PGD among the people left behind. "It's so sad. It's just heartbreaking," says Katherine Shear, a psychiatrist at Columbia University and founding director of the Center for Prolonged Grief in New York.

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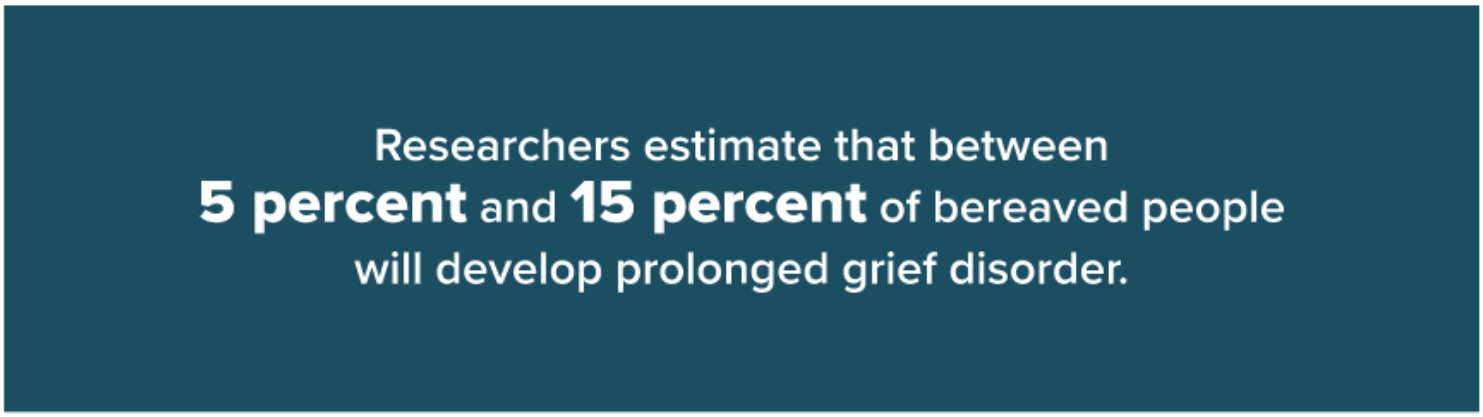
When grief gets complicated

In 2019, the steering committee of the DSM convened a workshop of bereavement experts to develop criteria to distinguish PGD from normal grief. One key feature: The acute symptoms of grief — numbness, emotional pain, trouble maintaining relationships and intense loneliness — last longer than usual. To avoid “pathologizing” the normal grief process, the committee chose 12 months as the cutoff where PGD begins, even though the disorder can often be diagnosed sooner.



SOURCE: H.G. PRIGERSON *ET AL / AR CLINICAL PSYCHOLOGY* 2021 KNOWABLE MAGAZINE

PGD also presents some features not usually found in normal grief, says Holly Prigerson, an epidemiologist at Weill Cornell Medicine in New York who played a key role in the development of the DSM criteria and coauthored a history of the diagnosis of PGD in the 2021 *Annual Review of Clinical Psychology*. Notable among these is identity disturbance: “People with PGD feel they are unsure of who they are, where they fit in, where they belong, that life lacks meaning and future lacks hope of joy,” Prigerson says.

[su_panel color=”#3A3A3A” border=”1px solid #3A3A3A” radius=”2? text_align=”left”]**If you or a loved one is having suicidal thoughts, please seek help.**

The National Suicide Prevention Lifeline (1-800-273-8255) is open 24 hours a day. Prefer to chat online? Go to the Lifeline’s homepage and click on the “chat” button in the top right corner.

The Means Matter Campaign of Harvard’s School of Public Health has an array of information and resources about suicide prevention.

A downloadable document tackling frequently asked questions about suicide and suicide prevention is

available from the National Institute of Mental Health./su_panel]

Moreover, researchers have noted differences in brain activity between people experiencing PGD and noncomplicated grief. In a study using functional magnetic resonance imaging, researchers saw that both types of grievers showed brain activity related to pain when they were reminded of their missing loved ones. But people experiencing PGD showed additional activity in a region called the nucleus accumbens, which is part of a brain pathway associated with rewards and yearning. Other neuroimaging studies have charted brain patterns in PGD that appear to match what is seen in people struggling with addiction, which also arises from problems in reward pathways.

PGD can be very disruptive, both for the people experiencing it and those around them. Research shows it is associated with an increased risk of a number of health problems, such as trouble sleeping, substance abuse, immune abnormalities, cancer and cardiovascular disease.

In one study, researchers interviewed 150 people when their spouses were admitted to the hospital and then multiple times after their spouses' deaths. Among those who developed traumatic grief (essentially the same as PGD, says Prigerson), 19 percent developed heart trouble, compared with only 5 percent of those who were experiencing normal grief. Fifteen percent of people experiencing traumatic grief were diagnosed with cancer within 25 months after the death of their spouses, while none of the normally grieving widows and widowers were.

Another sample of nearly 150 people experiencing complicated grief found that 65 percent had thoughts of wanting to die and 38 percent engaged in self-destructive behavior. Nine percent tried to kill themselves.

Grief "is absolutely normal," says Robert Neimeyer, a psychologist the University of Memphis. "Except when it's not."

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Covid as a complicating factor

In April 2020, researchers led by Maarten Eisma, a psychologist at the University of Groningen in the Netherlands, sounded an alarm: In a letter published in *Psychiatry Research*, they warned that rates of prolonged grief may spike during Covid-19. They pointed to previous tragedies, such as a 2008 earthquake in China, after which 70 percent of bereaved survivors had probable PGD, a much higher rate than usual. According to Eisma and his team, these data show that people are more likely to develop PGD after a sudden loss in a highly stressful environment.

The researchers' concerns around Covid were based on known risk factors for PGD, identified over the years through interviews with people who have experienced major losses. An example is the Yale Bereavement Study, in which researchers talked with hundreds of people in Connecticut who had lost a family member within the last six months, then spoke to them twice more, at an average of 11 and 20 months after the death. Based on this and other studies, researchers have compiled factors that appear to increase the risk of PGD. Most, says Neimeyer, relate to "who we are, who we lose and how we lose them."

Doctors in a California hospital work to intubate a Covid-19 patient in the ICU. As of March 2022, Covid-19 has killed more than 6 million people worldwide. Some researchers warn that the circumstances around deaths during the pandemic may heighten the risk for prolonged grief disorder among survivors. Credit: Reuters/Alamy Stock Photo

People are more likely to develop PGD after losing a child or romantic partner, for example, or when the death is sudden, unexpected or violent (via suicide, accident or murder). People who have a history of mood or anxiety disorders or substance abuse are also more likely to develop PGD.

Early traumas may predispose someone to PGD: Interviews with 85 widowed people showed that 43 percent of those who lost a parent during childhood developed traumatic grief years later when their spouse died, compared with 13 percent of those who didn't lose a parent at a young age. Among the sample, all of the people who were abused as children developed traumatic grief versus 14 percent of everyone else. Even where a loved one dies seems to matter: A study of caregivers of more than 300 cancer patients found that 22 percent of caregivers whose loved ones had died in hospital developed PGD. In contrast, only 5 percent of those whose loved ones had died at home with hospice care experienced prolonged grief.

It's too soon to know if losing someone to Covid may increase a person's risk of developing PGD. Some research suggests it might, but the data are mixed. Still, certain key aspects of the pandemic, such as perceived lack of support, are known risk factors for PGD.

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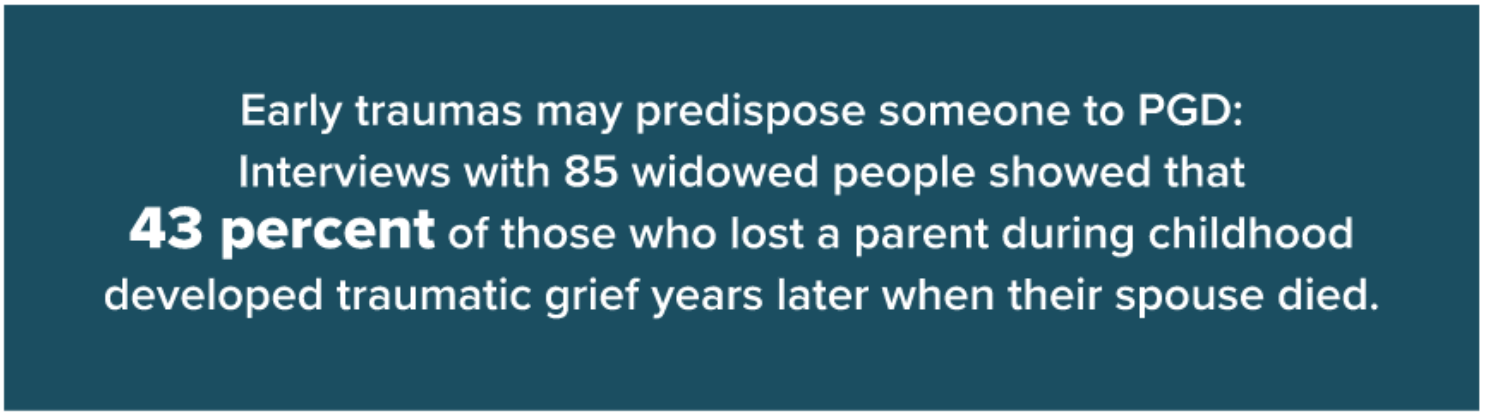
Tailored treatments

Psychotherapies and medications for normal grief and depression often don't work for PGD. But researchers have had some success using approaches tailored specifically to complicated grief. Some treatments — particularly cognitive behavioral therapy (CBT), which focuses on trying to help someone change unhealthy behaviors and thinking patterns — have been shown to help, and researchers continue to explore how to further improve treatment.

For instance, one 2014 study found that combining CBT with exposure therapy, in which the patient relives memories of their loved one's death, proved three times more effective for PGD than CBT alone. After 10 sessions of CBT and four sessions of exposure therapy, only 15 percent of participants still met the criteria for PGD.

Prigerson and other experts also note the effectiveness of a treatment protocol developed by Shear, of Columbia University, that uses elements of CBT but also draws on other approaches that, for instance, help the bereaved set personal goals, which can give them a sense of hope, enthusiasm and purpose. A 2005 study of 95 people with PGD found that more than half of those assigned to this 16-session protocol experienced a lessening of their symptoms, versus 28 percent of those given standard psychotherapy not tailored to PGD. Subsequent research — including a 2014 study of 150 people — also has reported that Shear's approach works better for PGD than standard therapy.

Researchers are exploring other options, including internet-based therapy that would begin soon after people at risk of developing PGD experienced bereavement. It would target the symptoms of PGD by helping people find ways to enjoy and re-engage in their lives.



SOURCE: K. SILVERMAN *ET AL* /
ISRAEL JOURNAL OF PSYCHIATRY AND RELATED SCIENCES 2001 KNOWABLE MAGAZINE

Given that activity in the brains of people with PGD resembles that in people struggling with addictions, Prigerson and others have suggested trying naltrexone, a drug that targets reward systems in people addicted to alcohol or opioids. The drug is being tested now for PGD, says Prigerson, but it's too early to tell whether it offers relief.

Like other forms of grief, PGD can get better with time, but it takes a lot longer, says Mancini, of Pace University. "That's why treatment can help. It can accelerate the process of recovery."

One key element of Shear's 16-session protocol involves making meaningful connections with other people. This element — finding people who can fill some of the roles vacated by a lost loved one — was key to my recovery from PGD. I had years of psychotherapy that wasn't tailored to PGD, but a turningpoint came when my daughter was born, seven years after my mother died.

The instant the nurses placed her sticky, screaming body on my chest, a heavy feeling I'd been carrying around lifted. I had the intimacy of a mother-daughter relationship back — I was just on the other side of it.

Alison McCook is a writer and editor based near Philadelphia. She can talk about grief and loss for days. Follow Alison on Twitter @alisonmccook

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