

How Long Should It Take to Grieve? Psychiatry Has Come Up With an Answer.

The latest edition of the DSM-5, sometimes known as “psychiatry’s bible,” includes a controversial new diagnosis: prolonged grief disorder.

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Holly Prigerson, a professor of sociology in medicine, has worked to include prolonged grief as a classified, diagnosable psychiatric disorder. Hiroko Masuike/The New York Times

After more than a decade of argument, psychiatry's most powerful body in the United States added a new disorder this week to its diagnostic manual: prolonged grief.

The decision marks an end to a long debate within the field of mental health, steering researchers and clinicians to view intense grief as a target for medical treatment, at a moment when many Americans are overwhelmed by loss.

The new diagnosis, prolonged grief disorder, was designed to apply to a narrow slice of the population who are incapacitated, pining and ruminating a year after a loss, and unable to return to previous activities.

Its inclusion in the Diagnostic and Statistical Manual of Mental Disorders means that clinicians can now bill insurance companies for treating people for the condition.

It will most likely open a stream of funding for research into treatments — naltrexone, a drug used to help treat addiction, is currently in clinical trials as a form of grief therapy — and set off a competition for approval of medicines by the Food and Drug Administration.

Since the 1990s, a number of researchers have argued that intense forms of grief should be classified as a mental illness, saying that society tends to accept the suffering of bereaved people as natural and that it fails to steer them toward treatment that could help.

A diagnosis, they hope, will allow clinicians to aid a part of the population that has, throughout history, withdrawn into isolation after terrible losses.

"They were the widows who wore black for the rest of their lives, who withdrew from social contacts and lived the rest of their lives in memory of the husband or wife who they had lost," said Dr. Paul S. Appelbaum, who is chair of the steering committee overseeing revisions to the fifth edition of the D.S.M.

"They were the parents who never got over it, and that was how we talked about them," he said. "Colloquially, we would say they never got over the loss

of that child.”

Throughout that time, critics of the idea have argued vigorously against categorizing grief as a mental disorder, saying that the designation risks pathologizing a fundamental aspect of the human experience.

They warn that there will be false positives — grieving people told by doctors that they have mental illnesses when they are actually emerging, slowly but naturally, from their losses.

And they fear grief will be seen as a growth market by drug companies that will try to persuade the public that they need medical treatment to emerge from mourning.

“I completely, utterly disagree that grief is a mental illness,” said Joanne Cacciatore, an associate professor of social work at Arizona State University who has published widely on grief, and who operates the Selah Carefarm, a retreat for bereaved people.

“When someone who is a quote-unquote expert tells us we are disordered and we are feeling very vulnerable and feeling overwhelmed, we no longer trust ourselves and our emotions,” Dr. Cacciatore said. “To me, that is an incredibly dangerous move, and short sighted.”

“I completely, utterly disagree that grief is a mental illness,” said Joanne Cacciatore, an associate professor of social work at Arizona State University who operates the Selah Carefarm, a retreat for bereaved people. Adriana Zehbrauskas for The New York Times

‘We don’t worry about grief’

The origins of the new diagnosis can be traced back to the 1990s, when Holly G. Prigerson, a psychiatric epidemiologist, was studying a group of patients in late life, gathering data on the effectiveness of depression treatment.

She noticed something odd: In many cases, patients were responding well to

antidepressant medications, but their grief, as measured by a standard inventory of questions, was unaffected, remaining stubbornly high. When she pointed this out to psychiatrists on the team, they showed little interest.

"Grief is normal," she recalls being told. "We're psychiatrists, and we don't worry about grief. We worry about depression and anxiety." Her response was, "Well, how do you know that's not a problem?"

Dr. Prigerson set about gathering data. Many symptoms of intense grief, like "yearning and pining and craving," were distinct from depression, she concluded, and predicted bad outcomes like high blood pressure and suicidal ideation.

Her research showed that for most people, symptoms of grief peaked in the six months after the death. A group of outliers — she estimates it at 4 percent of bereaved individuals — remained "stuck and miserable," she said, and would continue to struggle with mood, functioning and sleep over the long term.

"You're not getting another soul mate and you're kind of eking out your days," she said.

In 2010, when the American Psychiatric Association proposed expanding the definition of depression to include grieving people, it provoked a backlash, feeding into a broader critique that mental health professionals were overdiagnosing and overmedicating patients.

"You've got to understand that clinicians want diagnoses so they can categorize people coming through the door and get reimbursement," said Jerome C. Wakefield, a professor of social work at New York University. "That is a huge pressure on the D.S.M."

Still, researchers kept working on grief, increasingly viewing it as distinct from depression and more closely related to stress disorders, like post-

traumatic stress disorder. Among them was Dr. M. Katherine Shear, a psychiatry professor at Columbia University, who developed a 16-week program of psychotherapy that draws heavily on exposure techniques used for victims of trauma.

By 2016, data from clinical trials showed that Dr. Shear's therapy had good results for patients suffering from intense grief, and that it outperformed antidepressants and other depression therapies. Those findings bolstered the argument for including the new diagnosis in the manual, said Dr. Appelbaum, who is chair of the committee in charge of revisions to the manual.

In 2019, Dr. Appelbaum convened a group that included Dr. Shear, of Columbia, and Dr. Prigerson, now a professor at Weill Cornell Medical College, to agree on criteria that would distinguish normal grief from the disorder.

The most sensitive question of all was this: How long is prolonged?

Though both teams of researchers felt that they could identify the disorder six months after a bereavement, the A.P.A. "begged and pleaded" to define the syndrome more conservatively — a year after death — to avoid a public backlash, Dr. Prigerson said.

"I have to say that they were kind of politically smart about that," she added. The concern was that the public was "going to be outraged, because everyone feels because they still feel some grief — even if it's their grandmother at six months, they are still missing them," she said. "It just seems like you're pathologizing love."

Measured at the year mark, she said, the criteria should apply to around 4 percent of bereaved people.

The new diagnosis, published this week in the manual's revised edition, is a

breakthrough for those who have argued, for years, that intensely grieving people need tailored treatment.

"It's kind of like the bar mitzvah of diagnoses," said Dr. Kenneth S. Kendler, a professor of psychiatry at Virginia Commonwealth University who has played an important role in the last three editions of the diagnostic manual.

"It's sort of an official blessing in the world," he said. "If we were on the planetary committee of the American Astronomical Society deciding what is a planet or not — this one's in, and Pluto we kicked out."

If the diagnosis comes into common use, it is likely to popularize Dr. Shear's treatment and also give rise to a range of new ones, including drug treatments and online interventions.

Dr. Shear said it was difficult to predict what treatments would emerge.

"I don't really have any idea, because I don't know when the last time there was a really brand-new diagnosis," she said.

She added, "I really am in favor of anything that helps people, honestly."

Dr. M. Katherine Shear, a psychiatry professor at Columbia University and a founding director of the Center for Prolonged Grief, has been studying the condition since 1995. Yana Paskova for The New York Times

A loop of grief

Amy Cuzzola-Kern, 54, said Dr. Shear's treatment helped her break out of a terrible loop.

Three years earlier, her brother had died suddenly in his sleep of a heart attack. Ms. Cuzzola-Kern found herself compulsively replaying the days and hours leading up to his death, wondering whether she should have noticed he was unwell or nudged him to go to the emergency room.

She had withdrawn from social life and had trouble sleeping through the

night. Though she had begun a course of antidepressants and seen two therapists, nothing seemed to be working.

"I was in such a state of protest — this can't be, this is a dream," she said. "I felt like I was living in a suspended reality."

She entered Dr. Shear's 16-session program, called prolonged grief disorder therapy. In sessions with a therapist, she would narrate her recollection of the day that she learned her brother had died — a painful process, but one that gradually drained the horror out of the memory. By the end, she said, she had accepted the fact of his death.

The diagnosis, she said, mattered only because it was a gateway to the proper treatment.

"Am I ashamed or embarrassed? Do I feel pathological? No," she said. "I needed professional help."

Yet, others interviewed said they were wary of any expectation that grief should lift in a particular period of time.

"We would never put a time frame around when someone should or shouldn't feel that they have moved forward," said Catrina Clemens, who oversees the victim services department of Mothers Against Drunk Driving, which provides services to bereaved relatives and friends. The organization encourages bereaved people to seek mental health care, but has no role in diagnosis, said a spokesperson.

Filipp Brunshteyn, whose 3-year-old daughter died after an automobile accident in 2016, said grieving people could be set back by the message that their response was dysfunctional.

"Anything we inject into this journey that says, 'that's not normal,' that could cause more harm than good," he said. "You are already dealing with someone very vulnerable, and they need validation."

To set a year as a point for diagnosis is "arbitrary and kind of cruel," said Ann Hood, whose memoir, "Comfort: A Journey Through Grief," describes the death of her 5-year-old daughter from a strep infection. Her own experience, she said, was "full of peaks and valleys and surprises."

The first time Ms. Hood walked into her daughter Grace's room after her death, she saw a pair of ballet tights lying in a tangle on the floor where the little girl had dropped them. She screamed. "Not the kind of scream that comes from fright," she later wrote, "but the kind that comes from the deepest grief imaginable."

She slammed the door, left the room untouched and eventually turned off the heat to that part of the house. At the one-year mark, a well-meaning friend told her it was time to clear out the room — "nothing worse than a shrine," he told her — but she ignored him.

Then one morning, three years after Grace's death, Ms. Hood woke up and returned to the room. She sorted her daughter's clothes and toys into plastic bins, emptied the bureau and closet and lined up her little shoes at the top of the stairs.

To this day, she is not sure how she got from one point to the other. "All of a sudden, you look up," she said, "and a few years have gone by, and you're back in the world."