

Managing Big Emotions Around MASH



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A big diagnosis can trigger all kinds of feelings. It's true of any chronic condition, including [metabolic dysfunction-associated steatohepatitis \(MASH\)](#). This type of liver disease is not caused by alcohol use. It happens when fat builds up in the liver.



A chronic condition like MASH brings up many emotions, but like your condition they can be managed. (Photo Credit: E+/Getty Images)

Whether you're newly diagnosed or you've been living with MASH for years, the emotional journey can be overwhelming, says Kerry Sivia, 41, who has stage IV MASH with [cirrhosis](#). It can take weeks or months to get a firm diagnosis, such as stage II MASH with liver inflammation, or stage III MASH with fibrosis (liver scarring). You may need to have many tests and scans and adopt a new lifestyle. Talking about your diagnosis can feel uncomfortable. These experiences and the difficult emotions involved are normal for people with MASH.

"It's OK to grieve that this has happened to you and that it's stressful," says Kelly DeMartini, PhD, a Yale School of Medicine psychologist and researcher. She encourages "being very honest about the whole range of emotions that come with it."

You can also let yourself feel optimistic, says Sivia, who volunteers with the American Liver Foundation. "Even on the difficult days, you can gain quite a bit of health from this," she says.

How Do You Manage Feelings When You Have MASH?

MASH is often a silent disease. It's very common not to have any symptoms until later stages, or until you've developed cirrhosis. Emotions can vary widely when the diagnosis comes.

Shock, fear, and uncertainty

"The diagnosis itself can be accompanied with a bit of shock," says DeMartini. "It often comes out of the blue."

That was the case for Sivia, who was diagnosed at age 36 after a visit to her regular doctor for swollen ankles. Sivia spent the night in the emergency room, where she had blood tests, an ultrasound, and a CT scan. It was all happening during the COVID-19 pandemic, so she was unable to bring family with her. She'd never been hospitalized before and left the next day without firm answers.

"I just was so shocked by all of this," she says. "For patients, probably the scariest part is not knowing, 'Am I going to be OK?'"

There are ways to manage feeling shocked, scared, or uncertain after a MASH diagnosis. DeMartini encourages patients to reframe their outlook. Instead of thinking of your experiences as specific to liver disease, remember that shock and fear are "so normal and understandable" among people with any chronic illness. This outlook can help you feel less alone and may make it easier to deal with the condition.

Skip to main content and shame

People who have chronic conditions often blame themselves for getting sick. It's the same with MASH. A diagnosis can lead to feelings of guilt and shame about your past habits. Being overweight or having obesity can lead to [high blood pressure](#), [diabetes](#), and [high cholesterol](#),

"Sometimes, the people I work with also feel that they brought on their own chronic illness because their faith wasn't strong enough, they worked too hard and neglected their physical health, or because it is a punishment," says Natalia Alas Duran, LCSW-S, LICSW, a licensed clinical social worker based in Austin, Texas.

Self-blame can cause even more emotional pain and distress. You might withdraw from friends and family, making it harder to adopt new habits to improve your health. Finding ways to deal with guilt and shame is important.

"These emotions can be managed through self-compassion, allowing yourself to make room for the 'bad' feelings, and reaching out for help when needed," Alas Duran says. She also advises patients not to "push through" or go without rest when difficult feelings slow them down.

Anxiety

Managing MASH involves different and frequent tests.

"It is jarring, especially at the beginning," Sivia said.

Your doctor will test your blood to see if your liver enzyme levels are high. Imaging studies such as ultrasounds, MRI, and CT scans measure liver fat and scarring. Other ultrasound-based scans measure liver stiffness, which can be a sign of fibrosis. Biopsies are sometimes used to diagnose MASH and determine the stage of your disease.

After her diagnosis, Sivia needed weekly [tests of her liver enzymes](#). "It was nerve-racking," she said. "I wanted to know what everything meant." Over time, the tests became less frequent. Now, she has imaging done every six months to look for lesions. Trusting her doctors makes the waiting easier, she says.

"Those feelings of anxiety and worry waiting for scan results are completely normal," DeMartini says. She helps patients take steps to "feel more in control." For instance, after a test, ask your doctor how and when you'll get your results. That way, you won't be checking your emails or waiting for a phone call.

The shock of your initial diagnosis can also make you feel more vulnerable, leading to anxiety around unfamiliar symptoms.

"Some individuals may lose a sense of trust in their body. Any new physical sensation or change can invoke anxiety," Alas Duran says. During periods of anxiety, she reminds patients to tend to their basic needs, like getting enough rest and making time for hobbies, "so we have more capacity to manage the big feelings that can come with living with chronic illness."

Sadness, frustration, and isolation

Changing your habits to help manage MASH can make you feel frustrated, sad, and isolated. Maybe you need to prepare healthy meals at home and limit visits to your favorite restaurant. You could also struggle to adopt new exercise and sleep routines. Feelings of frustration and sadness can lead you to withdraw from the people and activities that make you happy, leading to isolation.

DeMartini advises all of her patients to stop drinking alcohol and eat lower-fat protein sources. Those lifestyle changes can be "overwhelming," she said, especially for patients who never saw liver disease coming. They may have a genetic predisposition to liver disease, instead of their past habits affecting their condition.

Just before her diagnosis, Sivia had bought a new pair of sneakers and planned to take up walking. But finding out she was sick "took the wind out of my sails," she said. "I let those walking shoes sit there for three months." Encouraged by her family, she eventually started walking daily and following the Mediterranean diet. Within a few months, she'd lost 30 pounds. Then she lost about 80 more. "I no longer have fat in my liver, which is a good thing. I started out at 310 pounds, and I'm now 200," Sivia said.

If you're struggling to find time for exercise, Sivia advises walking whenever you can. She'll often park at the far end of the parking lot, take stairs instead of elevators, walk the shopping mall, or spend half her lunch break walking.

Exercise has also made her feel less isolated. By participating in the Liver Life Walk, she's realized that many people with liver disease are still "living normal lives," she said. "Once you find people who are going through something like you, that makes you feel so much better."

What Do You Do When You Feel Stigmatized or Misunderstood?

Until 2023, MASH was called nonalcoholic fatty liver disease. Sivia felt the previous name stigmatized people who may struggle with addiction or weight. MASH is "a nondiscriminating disease" among people with very different bodies and backgrounds, she says. "It develops because of abuse to your liver, whether that's through autoimmune disease and your liver attacking itself, not having a great diet, or genetic factors."

Still, clinicians, family, friends, or people you've just met could suggest that having MASH is your fault. People might assume that you have liver disease because of past habits like alcohol abuse or not taking care of your health.

"Certainly some people have had experiences in the health care system with those who've promoted that belief that this is something to be ashamed of," DeMartini says. "But there's often this internalized stigma. People blame themselves, and then become concerned that other people will have the same thoughts that they're having."

If you blame yourself for your condition, you may be less likely to talk about your feelings and get the social support you need. A counselor or therapist can help you break negative thought patterns and learn new ways to talk about your disease. DeMartini helps patients with how to have those conversations with family members and friends "when they're scared that there is going to be judgment."

What Do You Do When Feelings Become Overwhelming?

It's important to manage your emotions when you have MASH. Over time, lifestyle adjustments and healthy habits can help you feel more in control of your disease, says DeMartini. She encourages "managing your own personal stress triggers, getting good sleep and exercise, and maintaining realistic hope, which involves being able to tolerate and express all of your emotions."

But there are times when it may help to speak to a therapist. In the past, Sivia has dealt with depression caused by hepatic encephalopathy, a brain condition related to liver dysfunction. She's unable to take antidepressants because of the damage to her liver.

"I needed to find other solutions," she says. "Talk therapy can do a lot for patients, to help them come to terms with things, to deal with stresses, to even just talk about different tests."

^C Skip to main content ^D5, such as those offered by the [American Liver Foundation](#), may be helpful for caregivers, patients, and transplant recipients.

Here are signs to be aware of that could indicate you or your loved one needs greater support:


- Feeling less able to deal with your day-to-day life than you were previously
- Noticing that you're disengaging from your friends and/or family
- Feeling more irritable, which is often a sign of anxiety and depression

Signs to watch for in a loved one:

- They're no longer engaging in activities that they used to find meaningful.
- They're having significant difficulty sleeping or not sleeping.
- They have minimal appetite, outside of what might be caused by changes in medication.

Family and friends should also pay close attention to their loved one's well-being when "significant new complications" arise in their disease, DeMartini says.

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