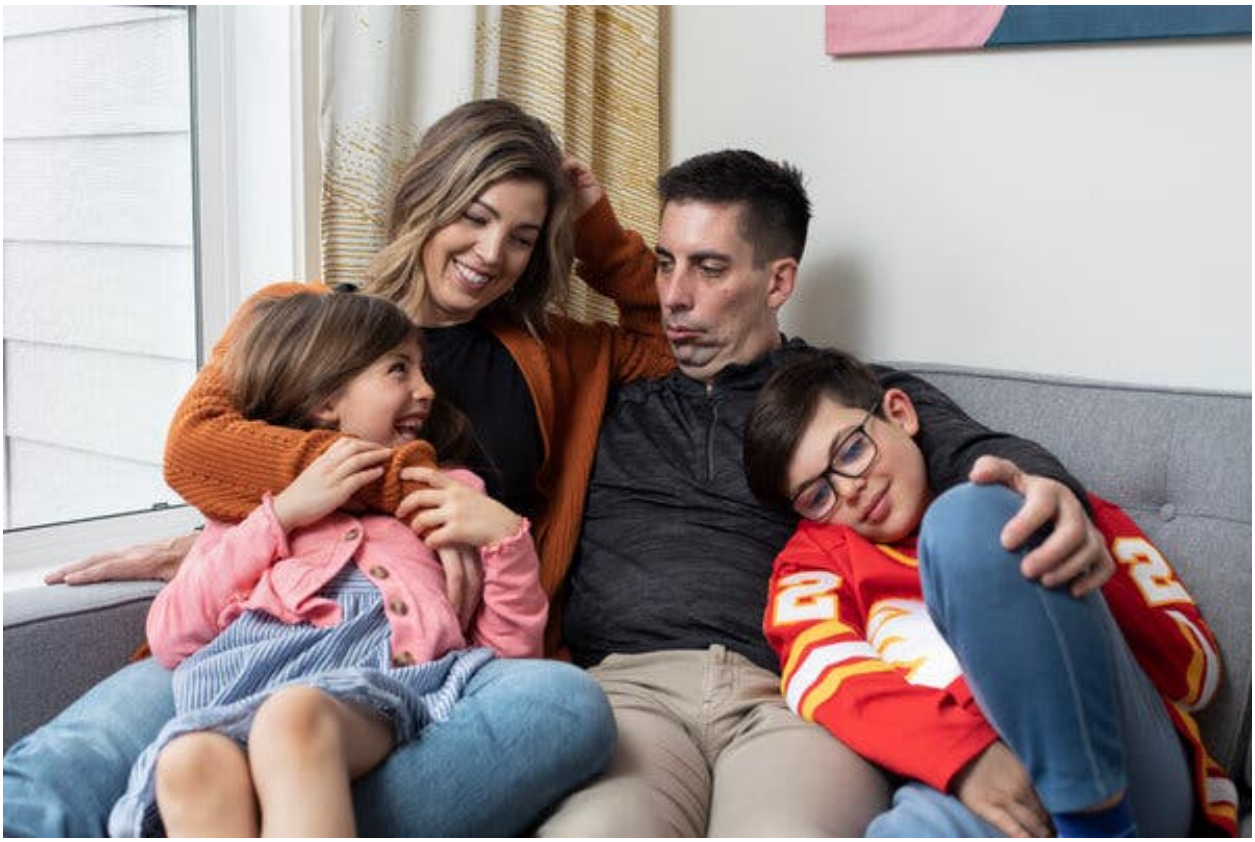
*The New York Times*

# *Chris Snow Finds That His Luck, Good and Bad, Is All in the Family*

*The Calgary Flames executive has lived with A.L.S. since 2019. The team he helped build is in the N.H.L. playoffs, and he is still here to see whatever happens.*



Kelsie and Chris Snow at home in Calgary with their children, Willa, 7, and Cohen, 10. “However this goes, and whether it ends or continues, our kids will be so much better for it,” Chris Snow said of his A.L.S. experience.

**By John Branch**
**Photographs by Amber Bracken**
May 3, 2022

CALGARY, Alberta — Luck comes in all disguises. For Chris Snow, an assistant general manager for the N.H.L.’s Calgary Flames, this is what lucky looks like, for now:

He was home on a Friday night, on the couch with his wife, Kelsie, and their children: Cohen, 10, and Willa, 7. Someone started a silly game — "slow-motion fights." At molasses speed, they traded fake punches to the jaw and exaggerated grimaces. It was a bout of laughter.

Willa, gaptoothed like an old-time hockey goon, shrieked.

"What's so funny?" Kelsie asked.

"Daddy's making faces," Willa said.

"Daddy can't make faces," Kelsie said.

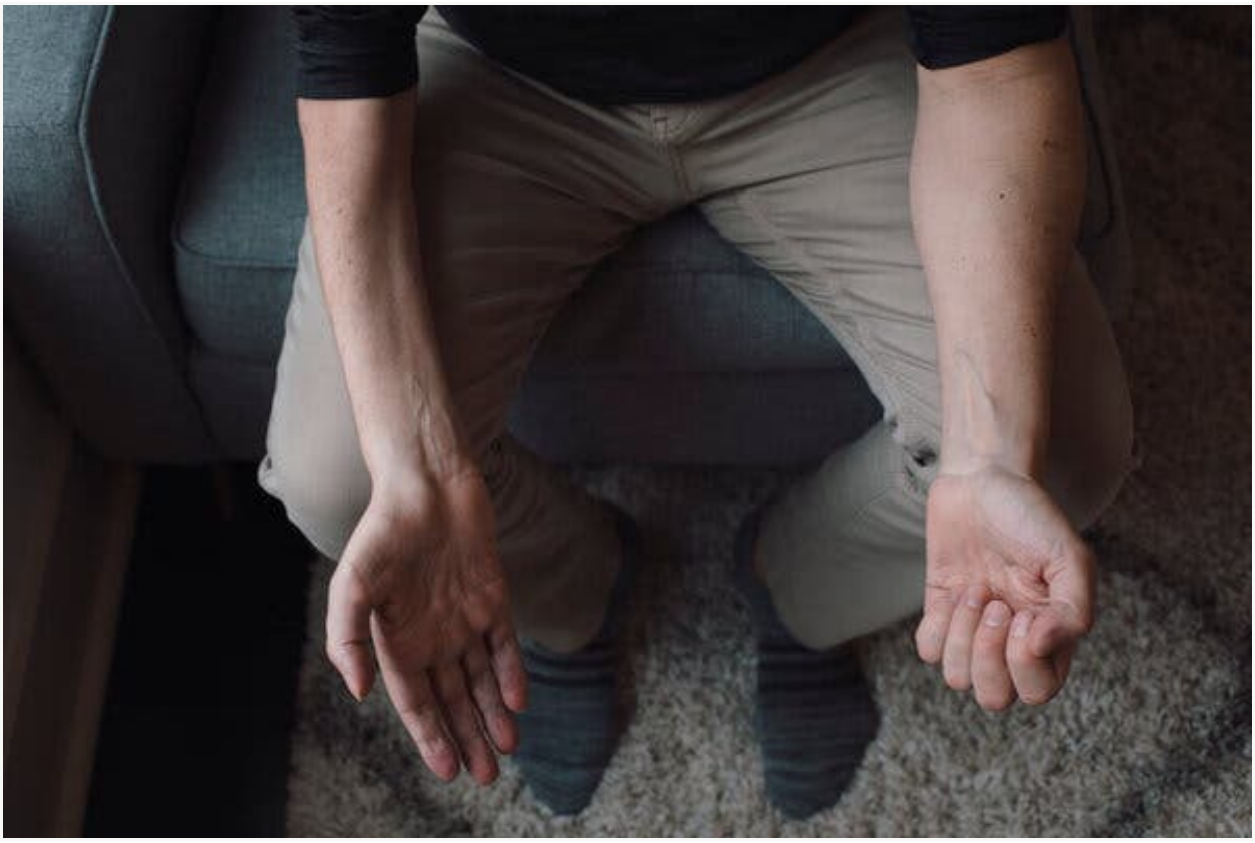
No, Chris Snow cannot make faces. Not anymore. At 40, he also cannot make a fake fist with one of his hands, and he cannot eat without a feeding tube.

But he is here, for now, and that feels like the luckiest thing in the world.

Three years ago, Snow was in a workout room at the Ritz Carlton in Denver during the first round of the Stanley Cup playoffs when the three outer fingers of his right hand suddenly felt weak.

About six months earlier, a genetic strain of amyotrophic lateral sclerosis, or A.L.S., killed Snow's father, nine months after diagnosis. It also killed two uncles and a cousin.

There was an anxious stream of appointments and tests, but A.L.S. is diagnosed only at the end of a process of eliminations. Maybe a pinched nerve? No. Maybe this, maybe that, maybe something else? No, no and no.



Three years ago, Snow felt a twinge of weakness in his right fingers. Within months, his right arm atrophied, but the disease has not spread to his left arm, surprising doctors.

Two months of dwindling hopes ended when Snow was diagnosed with A.L.S. in June 2019.

By then, his right arm had noticeably degenerated. A.L.S. spreads fast. Snow was expected to live no more than a year.

Three years later, the Flames have had their best regular season since 1989, when they last won the Stanley Cup. They won the Pacific Division and have visions of another championship run.

The biggest surprise to Calgary's postseason might be that Snow is here to see it.

He took a fake punch from Willa, fell back and rolled his eyes back in his head.

"Daddy's funny," Willa said.

A.L.S. has not taken him. Not yet.

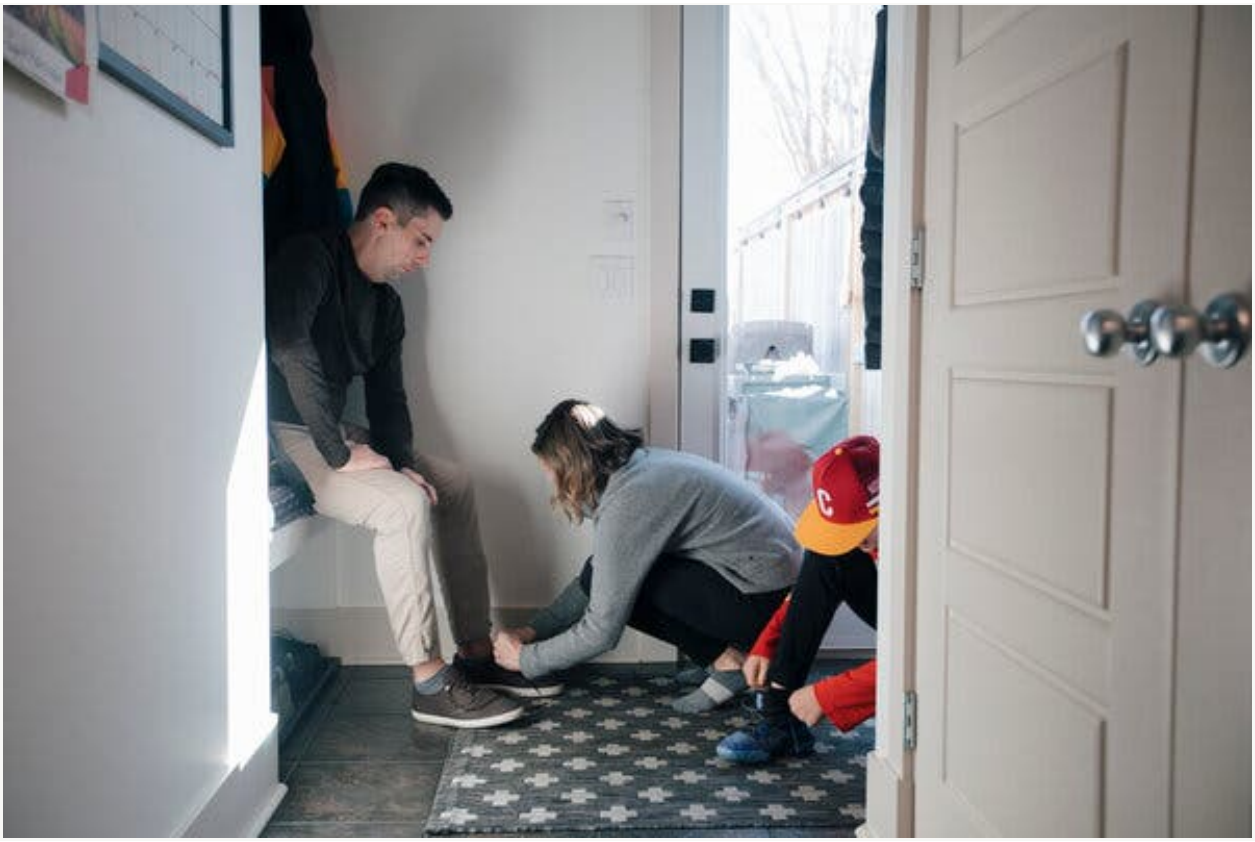
How lucky is that?

**‘This is the time of your life you have to do everything together.’**

There are two broad categories of A.L.S., the degenerative and fatal disease sometimes associated with Lou Gehrig, Stephen Hawking and the Ice Bucket Challenge.

About 90 percent of cases are classified as sporadic, appearing to inflict people randomly. About 10 percent of A.L.S. cases are familial, caused by a mutated gene. That is what Snow has. Odds of passing it to the next generation are 50-50.

“We’ve lost a lot of coin flips in the Snow family,” Kelsie said.



Cohen, right, ties his own shoes, but Chris needs help tying his. “Nothing about his life is different other than I tie his shoes and he doesn’t eat with his mouth,” said Kelsie said.

Most A.L.S. stories are the same, regardless of origin. The disease spreads, limb to limb, atrophying them into paralysis. Speaking, eating and breathing become increasingly difficult. Death often comes within a couple of years of the first symptoms.

One of Chris's uncles died of A.L.S. in 2004, at age 48. Another died in 2013, at 52. That uncle's son died in 2016 at age 28, 18 months after his diagnosis.

Then A.L.S. came for Chris's father.

"I was not scared until my dad was diagnosed," Chris said. In nine months, Bob Snow was gone at 68.

On the gut-punch day of June 10, 2019, when Chris's diagnosis was confirmed by a neurologist in Calgary, Chris and Kelsie melted in tears. But they also scrambled for answers. They contacted a doctor at the University of Miami, Michael Benatar, who studied the rare strain of familial A.L.S. that Snow's father had.

**The Fight Against A.L.S.**

The illness, also called Lou Gehrig's disease, robs people of their ability to move, speak, eat and ultimately breathe.

- **Lacking Evidence:** A new treatment held promise for slowing A.L.S., but an F.D.A. panel found that there's not enough data to show that it works.
- **Patient Voices:** Five people with A.L.S. speak about how their lives have changed as a result of this devastating illness.
- **Brain Implant:** A man who is fully paralyzed by A.L.S. was able to communicate using only his thoughts.
- **Rethinking Care:** In 2017, Brian Wallach was diagnosed with A.L.S. Now, his startup aims to help other patients make the most of their time.

A week later, the Snows left the children with friends and went to Florida. Tests probed Chris Snow's body and mind, analyzing his motor skills, his lung capacity, his memory. The couple went to lunch on a dreary day. We need a miracle, they told each other.

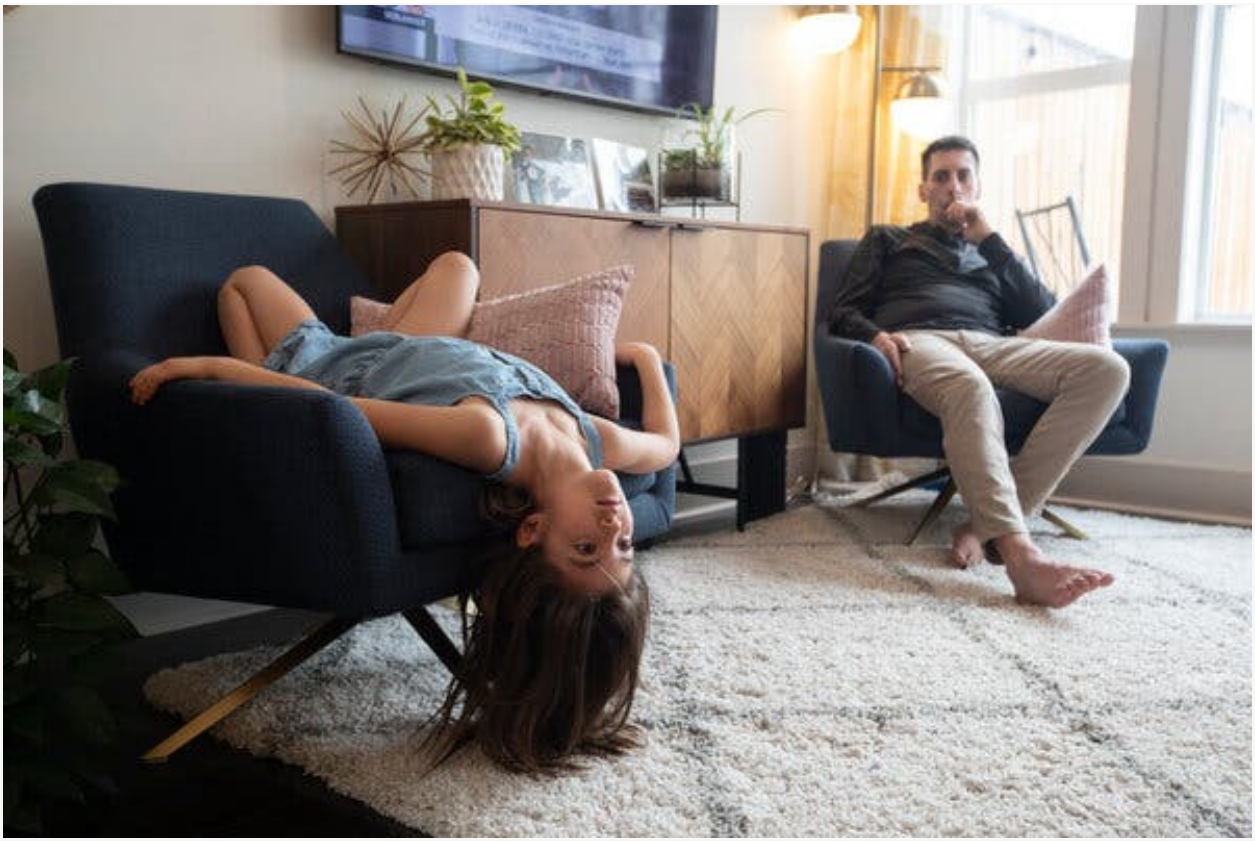
The miracle arrived in the form of a "but." Yes, you appear to have A.L.S. But you may be eligible for a promising gene-therapy trial.

Chris was the winner of the bad-luck lottery, as Kelsie said. He had the right kind of A.L.S. — a mutation of the SOD1 gene, which affects about 2 percent of all A.L.S. patients. The trial was entering its third phase.

Could it stop the decline entirely? The response remains etched in his mind: It is not outside the realm of possibility. Chris was enrolled.

Buoyed by the thought of living longer than a year, maybe even living for years, the Snows headed home, collected their children and went to Vancouver for the N.H.L. draft. They made plans for the best summer ever, believing — expecting — it could be their last one as a family.

“This is the time of your life you have to do everything together,” Snow said.



Snow, pictured with Willa, initially expected to live no more than a year. It has been three since his diagnosis. “I don’t spend much time, any time, thinking beyond today and tomorrow,” he said.

**An unusual career turn**

The Flames have three assistant general managers, including Craig Conroy, a former N.H.L. star. Snow's primary role is to oversee a complex digital warehouse for data and video, something he developed years ago as hockey's version of DiamondView. Other N.H.L. teams followed.

These days, thousands of data points from each game are collected from chips implanted in player uniforms and the puck. Every conceivable statistic is rendered and linked to a corresponding video with one click. Coaches, scouts and front-office personnel use the program to inform everything from power-play combinations to contract negotiations. Snow has three full-time employees.

Kelsie sometimes uses the movie "Moneyball" as shorthand to explain what Chris does for the Flames.

"The Jonah Hill character," she clarified.

"Not Brad Pitt," Chris said.

"Definitely not Brad Pitt," Kelsie said.

The two met in 2005. He was the confident young beat reporter covering the Red Sox for The Boston Globe, his hometown paper. She was the paper's summer intern from South Dakota. Romance bloomed in Fenway Park's press box.

Chris soon had career options. Sports Illustrated called. But then Doug Risebrough, the general manager of the Minnesota Wild at the time, offered Chris a vaguely defined front-office job. It was such an unusual career turn that Esquire wrote about it.

The couple moved to Minnesota, married in 2007, and Kelsie covered the Twins. But the Wild cleaned house after a few seasons and Chris landed as director of hockey analysis in Calgary in 2011. The Snows moved with newborn Cohen in tow.

A family photo of Chris with his son, Cohen, as a baby, taken before Chris's A.L.S. diagnosis.

By the time Snow was diagnosed with A.L.S. the children were 7 and 4. He could no longer clench his right hand. He could not cut meat or tie his shoes. But he insisted on working. The Flames promoted him to assistant general manager.

"It's identity," he said, sitting at his desk inside the Saddledome, where the Flames play. "It's being a provider. It's losing yourself in something. And it's showing our kids a model of ultimate resiliency."

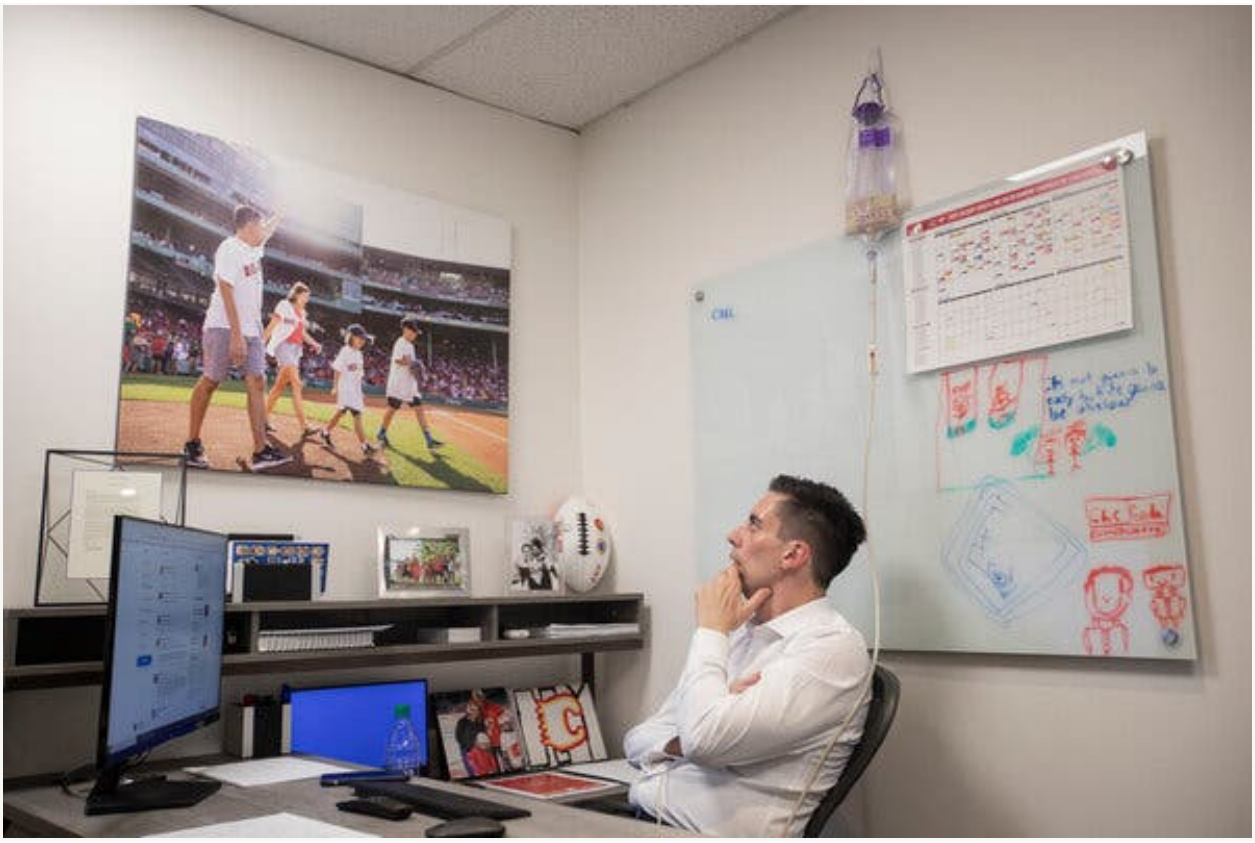
He paused. A family photo from Fenway Park hung behind him. All four Snows threw out first pitches there last fall.

"However this goes, and whether it ends or continues, our kids will be so much better for it," he said.

Treatments with a gene therapy produced by Biogen called Tofersen began in the summer of 2019, delivered by spinal tapevery four weeks in Toronto. For

the first six months, Snow could not be certain whether he was in the control group given a placebo. But almost immediately, atrophy slowed.

The Snows dared to dream that maybe the disease had stalled. Maybe Chris would merely live life without the use of a right arm.



Chris Snow in his office, eating with a feeding tube, before a game in Calgary on April 23.

"Of course, we know he is living with an illness that, so far, no one has survived," Kelsie wrote for Sports Illustrated in early 2020, adding: "I'll push aside my fear of losing him and be grateful for another day that Chris has simply, miraculously, stayed the same."

Then came the day before Easter in 2020. The family was sledding. Kelsie told Chris to smile for a photo. No, a better smile, she said. He tried. His broad, toothy grin was crooked on one side. Dread roared back.

"When this happened," Chris said, pointing to his face, "I was really, really scared."

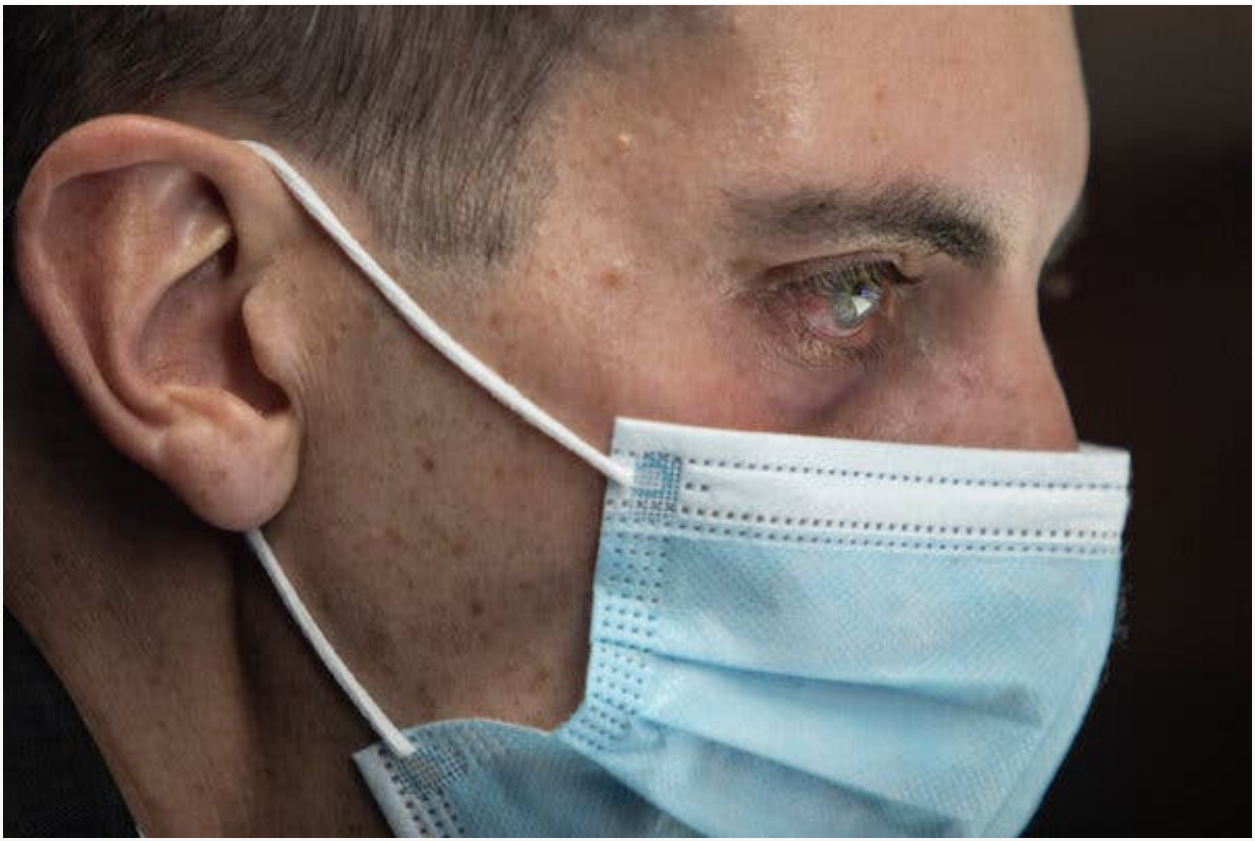
The decline was quick. His facial muscles atrophied; doctors soon found that even his eyelids were weak. Swallowing became difficult, then nearly impossible. His voice softened and his lower lip drooped. His face froze into a deadpan look.

Sometimes, one of the children that Chris coaches in baseball and hockey will say to Cohen or Willa that their father looks angry. They shrug. He always looks that way, they reply.

“It is really hard to show emotion,” Chris said. “Rarely does my voice do it, and never does my face do it.”

The coronavirus pandemic, with the wide use of masks, has allowed Snow to hide his drooped mouth.

“I still haven’t gotten over being self-conscious about my appearance,” he said.



Snow watching the Flames play in Calgary. He said he had been self-conscious about his looks since losing control of the muscles in his face, which has affected his ability to swallow and speak.

About six months after the first sign of a crooked smile in April 2020, Snow needed a feeding tube. It connects directly to his stomach, a few inches above and to the left of his belly button.

The goal is 4,000 calories a day, to offset the expected weight loss that comes with A.L.S. Some meals are store-bought formula, like Isosource, poured into an IV-style bag and fed into him with gravity.

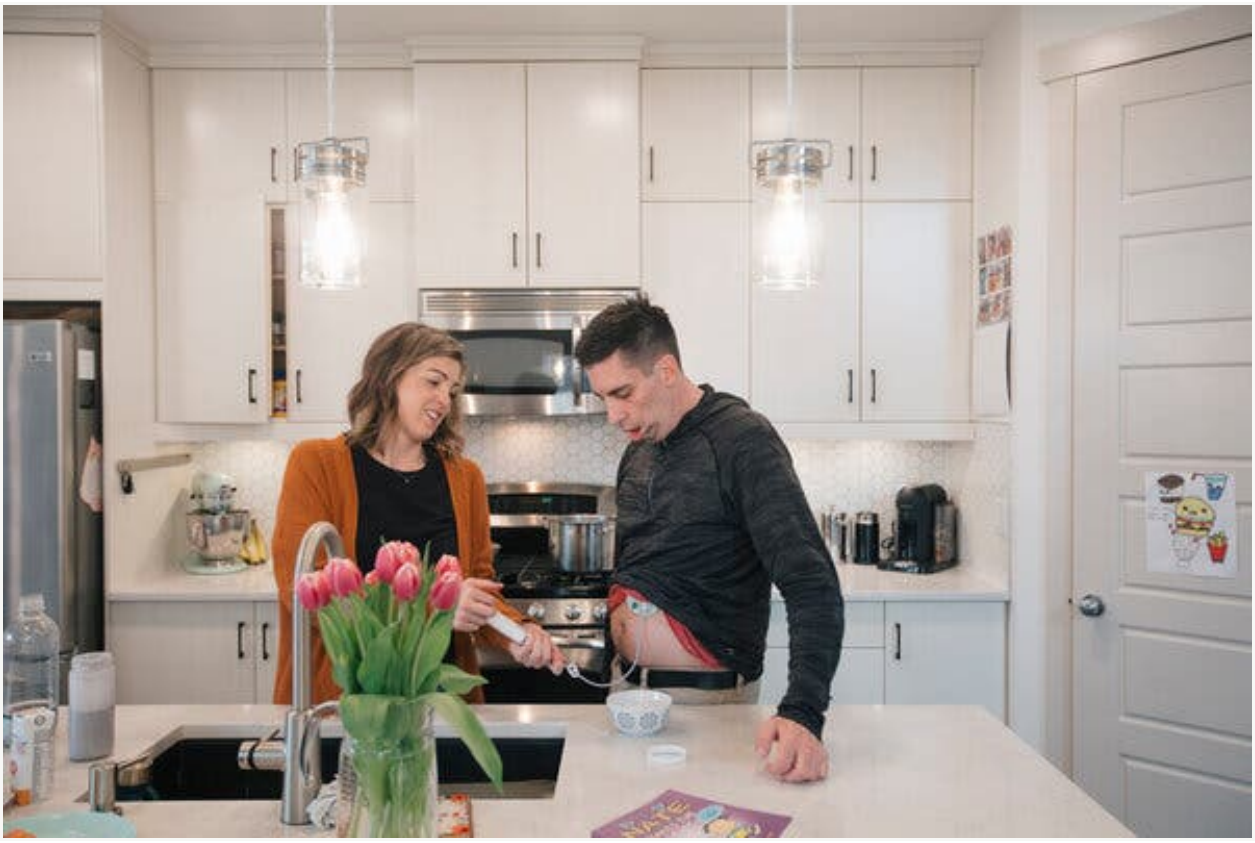
But Snow likes the idea of homemade food, even if he cannot taste it. Kelsie makes meals, a combination of blended ingredients — maybe oil, hemp hearts, milk and something like blueberries or spinach, measured and mixed to a viscosity that can be fed through his stomach tube with a syringe.

These days, Snow can sip water, coffee, even the occasional vodka tonic through his mouth. He uses his floppy right hand to hold his lips closed and sips from a cup held in his left.

Choking is a constant concern. Snow went on a Flames road trip last fall, carrying containers of liquid food. A late meal came up in the night, choking Snow and sending him to a Toronto hospital. A month later, at home, another choking episode awakened and terrified Cohen.

Snow takes anti-reflux medication and sleeps propped up on a pillow wedge. For months, things have steadied. He can still lift his right arm over his head, even do push-ups. His legs remain strong, as do his lungs — all positive signs in A.L.S. patients.

“We’re always waiting for the next shoe to drop,” Kelsie said.



Meals away from home come from store-bought formulas, but Chris prefers the blended concoctions that Kelsie makes, even if he cannot taste them.Credit...Amber Bracken for The New York Times

Chris still works every day in the office, attending all home games. The Flames expanded his small office so that it could fit a couch. Snow lies on it for meetings and calls because his voice is clearer, more full-throated, when he tilts his neck back.

He can be hard to understand, especially in the din of a crowd. Those close to him are used to it, like knowing someone with a thick accent.

Snow subconsciously keeps his left hand close to his chin, pushing his hanging lip closed until gravity drops it open again. When he speaks, he uses his left hand to help move his lower lip, almost like a puppeteer, to help with words that need closed lips for enunciation — like those with lots of P's, M's and B's.

Flames General Manager Brad Treliving admitted to a reflex to protect Snow, to lighten his workload, to make concessions. Snow notices when people treat him differently.

“I remember him telling me, ‘I’m not dead,’” Treliving said.

Snow recalled something his father told him: It’s not dying that scares him. It’s what comes before that.

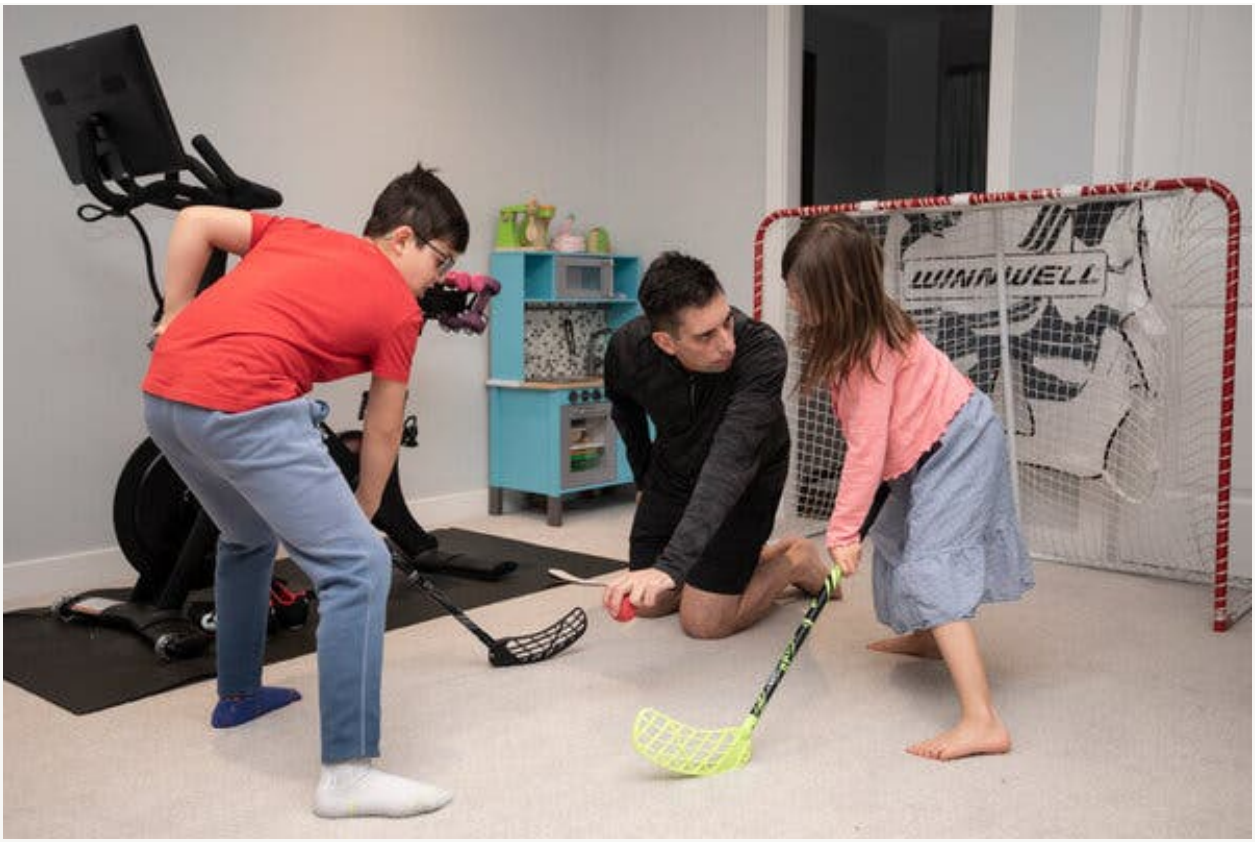
“I don’t spend much time, any time, thinking beyond today and tomorrow,” Snow said.

That is the Flames’ approach, too. There is no playbook for navigating the uncertainty. Decency is the rule.

“I roll with it,” Treliving said. “We’re not naïve. But you see what he’s been able to do already, so my mind doesn’t go there. I just don’t go there.”

It helps that the Snows do their best to lighten the darkness with humor.

“People are always surprised at how good he looks,” Kelsie said. “I tell him, they literally think you should be dead. The bar’s very low for you.”



Snow has lost his smile and the ability to swallow, but he still plays with his children every day.

The most meaningful hockey games might be in the basement, not the Saddledome. Chris plays goalie. He kneels, holding a miniature stick with his left hand. Cohen peppers him with shots of a squishy ball; Willa, on her dad's team, chases and tries to smack loose balls into a tiny goal across the expanse of soft carpet.

Chris provides the play-by-play. The kids push, argue, laugh, get sweaty. Chris belly laughs his approval.

The struggle — a struggle — is how to live for today while preparing for the future.

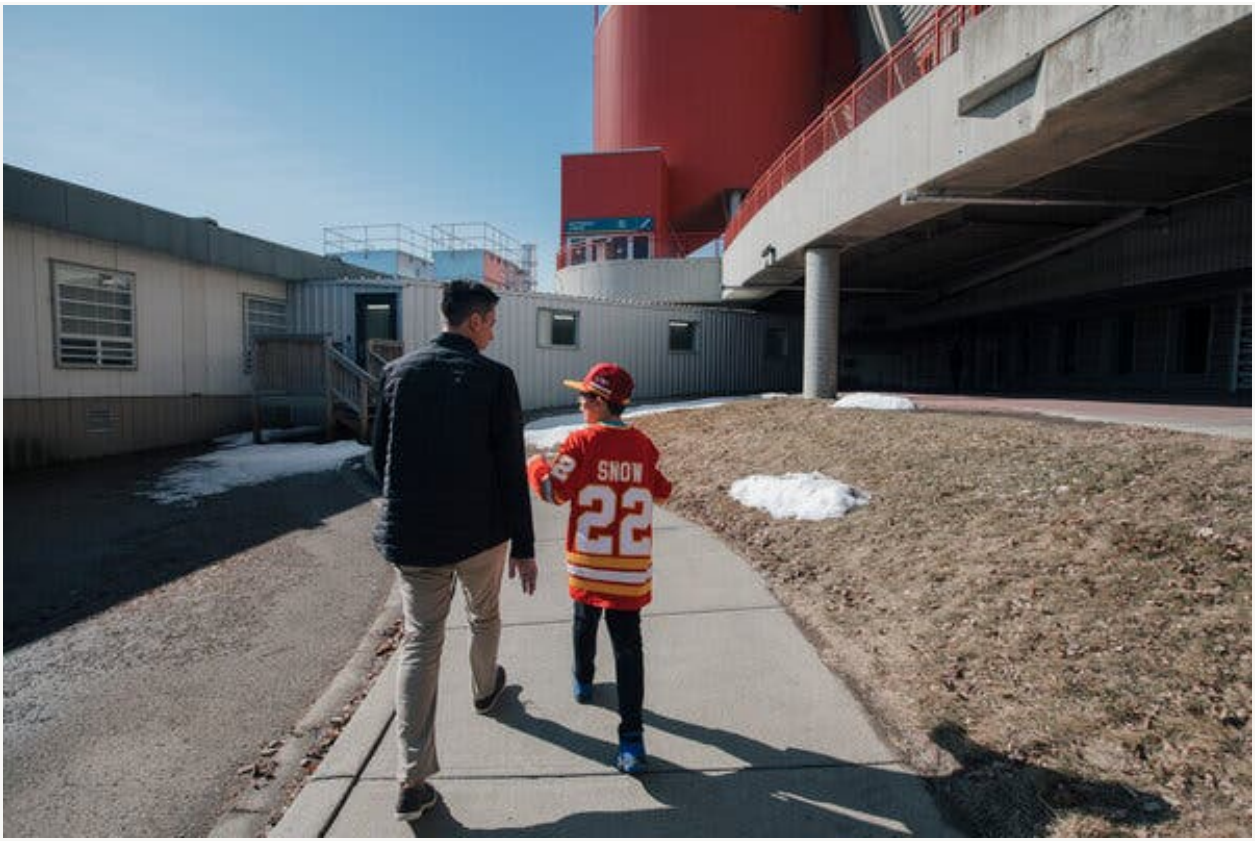
"It's a stay of execution, right?" Kelsie said. "You're going to die. But maybe not. Or maybe not for a long time."

The questions range from philosophical to practical. Will Chris be able to use the stairs in a few months? His left hand has lost a hint of strength, but it feels like the decline has plateaued. Is that for now, or forever? What happens if and when Chris is gone? The Snows try to chase away the what-ifs.

One uncertainty hangs heaviest: the genetic coin flip facing the children. The Snows have tried to put that, too, out of mind, with their doctor's help.

"We're going to cure familial A.L.S. in the not-too-distant future," said Dr. Lorne Zinman, director of the A.L.S. Clinic at Sunnybrook Research Institute in Toronto, who enrolled Snow in the study and oversees his care. "And I tell Kelsie and other families, do not worry about your kids. We're going to get there by then."

Last fall, the Tofersen trial ended with uneven results — officially, it did not meet its goals, leaving its future approval uncertain. But Snow will continue the monthly infusions, believing that they have slowed the progression and spread of his A.L.S.
Image



Chris Snow and his son, Cohen, head into the Saddledome on game day. Chris insists on working despite his fatal diagnosis. “I remember him telling me, ‘I’m not dead,’” his boss said.

The Snows are comfortable putting a face on A.L.S., providing rare hope and real talk. Kelsie spent the early part of the ordeal writing a blog that has evolved into a podcast called, “Sorry, I’m Sad.” It mostly highlights the stories of others.

“I found there were a lot of people who, when they heard a sad story, wanted a chance to tell their sad story — a space,” she said. “I thought there should be more spaces for this.”

There are fleeting moments when things feel perfect. In March, the Snows were sworn in as Canadian citizens. Chris plays regular games of poker with friends on the back deck. Last week, the family went skiing and Chris carved perfect turns.

Now there is a team dreaming of a Stanley Cup.

Before the playoffs, while being fed through a tube, Chris said how lucky he was.

And on the front porch later, her family cocooned inside, Kelsie said the same thing.

“It’s crazy,” she said, squinting into the warm and falling sun, “how your definition of luck changes.”

***Correction:***
***May 3, 2022***

*An earlier version of this article misstated a part of the name of a baseball statistical analysis program. It is DiamondView, not DiamondVision.*

John Branch is a sports reporter. He won the 2013 Pulitzer Prize for feature writing for “Snow Fall,” a story about a deadly avalanche in Washington State, and is the author of three books, including “Sidecountry,” a collection of New York Times stories, in 2021. @JohnBranchNYT

- 
- 

https://www.nytimes.com/2022/05/03/sports/hockey/chris-snow-calgary-flames-als.html?campaign_id=32&emc=edit_sp_20220505&instance_id=60543&nl=sports&regi_id=177901256&segment_id=91400&te=1&user_id=eac38c6faf1f143145c18ad20dab966b