



# IC THROUGH THE YEARS

Managing the condition at different stages of life.

*By Mark Toner*

Interstitial cystitis (IC) is an intensely personal disease. With no known cause or cure, the condition can strike people at any stage in their lives—from childhood through college and early adulthood, the prime of life, and well into retirement and the golden years.

Little is known about how the condition differs at varying ages, though recent research has confirmed noticeable differences in symptoms between younger and older patients. Nor does treatment vary dramatically—doctors may be more suspicious of other serious conditions such as malignancies when an older patient presents with symptoms for the first time, but the medical approach remains largely the same regardless of a patient's age.

But IC, like other chronic illnesses, isn't only about physical symptoms. It impacts every part of a person's life and can have a significant, even life-altering, effect as patients move through not only their journey with the condition, but also through the different stages of their lives.

In this article, we look at how IC has impacted people across a broad spectrum of ages and life stages, and discuss ways they—and others—have found to cope. It's important to remember that the physical piece is only one small part of a lifelong approach to coping with IC, argues Alexandra T. Milspaw, PhD, LPC, counselor and educator specializing in sexual health and chronic pain issues.



# YOUTH YOUNG ADULTS PRIME OF LIFE GOLDEN YEARS

“Whenever I start working with someone, I focus on four quadrants—mind, body, health, and spirit,” Dr. Milspaw says. “When we’re talking about what they’re not able to do physically, you’re very much within [only] one quadrant of experience.”

## Age: More Than a Number

IC used to be thought of as a disease that predominantly struck women in their 40s, 50s, and 60s. Patients with IC’s telltale symptoms outside of that age bracket were often misdiagnosed—or not diagnosed at all. But with growing understanding of IC among physicians and patients, more and more patients under 30 and over 60 have been diagnosed in recent years.

In 2012, researchers at North Shore-Long Island Jewish Health system in New York conducted the first-ever study that looked at IC patients specifically by age. Researchers analyzed nearly 270 patients with IC or painful bladder syndrome who had been treated between 1990 and 2008.

Ranging in age from 11 to 88 at the time of diagnosis, the patient population in the study reflected two growing trends: earlier diagnosis of IC symptoms in younger patients and the growing attribution of urinary problems in elderly patients to IC instead of other conditions associated with aging, such as overactive bladder.

The research confirmed earlier studies that found that younger IC patients were less likely to have Hunner’s lesions (found in 12 percent of patients under 30, compared to 42 percent of patients between 30 and 60 and 39.8 percent in those over 60). It also found that symptoms varied by age—younger IC patients were more likely to experience symptoms like urgency, frequency, and pain in their external genitalia and/or during sexual intercourse. Older patients, by contrast, more commonly reported additional issues with getting up to urinate more frequently at night (nocturia) and urinary incontinence.

The patients studied “portrayed unique symptom profiles for the youngest and oldest age cohorts, which is important for the efficient and accurate diagnosis of these specific patient groups who were previously diagnosed late or misdiagnosed,” the researchers wrote.

Broader research on how the body and mind process pain also suggests important differences by age, particularly among the youngest and oldest populations. One study found that chronic pain is as prevalent in children between 8 and 16 as in adults, while more than half of elderly people have chronic pain, according to a literature review cited in *Pain and Age* by Serge Marchand, Ph.D, neurophysiologist, professor of neurosurgery, and director of the Etienne-Le Bel Research Center of Sherbrooke University Hospital in Quebec.

Yet researchers found that the youngest and oldest patients typically receive the least pain medication—in part because of longstanding assumptions, such as the idea that pain is just part of growing old. “Pain is not a normal consequence of aging, since pathology is always involved,” Dr. Marchand writes.

Along with physical symptoms like pain, IC and other chronic conditions pose very different challenges at different stages of life, which we explore in greater detail in the pages that follow.



# YOUTH

With its maelstrom of social, physical, and emotional changes, adolescence is tough to navigate—even without a chronic and potentially embarrassing condition like IC.

“As a teenager, the last thing you want to talk about is bladder issues,” says Jean Egan, whose daughter Annie was diagnosed with IC at 14 (see profile, below).

The onset of puberty and the pain that comes from menstruation can also mask IC symptoms, making the condition more difficult to diagnose in young women, according to Milspaw. The one potential bright side is that the younger people are when they first face chronic pain, the more resilient they tend to be, she says. “If you’re looking at this from a chronic pain perspective, theoretically they could have less accumulation of stress and trauma and be more resilient,” she says. “On the other hand, the science

behind pain is really young and developing, so it’s not clear.”

Adolescents share one common setting—school, where they are typically required to sit for long periods of time and minimize disruptions. However, accommodations can—and should—be made for children struggling with IC. For example, Egan made sure Annie was put on a 504 plan, a federally mandated component of the Americans with Disabilities Act that outlines the accommodations a school is legally required to provide for a student with physical or mental conditions, including chronic illnesses like IC. In Annie’s case, that included an agreement that allowed her to make unlimited trips to the restroom. “If a teacher was in the middle of a lecture, she was able to get up and go without any questions asked,” Egan says.

Navigating relationships with peers can be more challenging for adolescents. “You see a lot of social isolation take place in all ages sometimes, but it’s really intense for that age group when the social part of the brain is really developing,” Milspaw says. One key question adolescents with IC must answer for themselves is what they want their friends and peers to know—and how to tell them.

“We brainstorm ways to describe their symptoms in ways other people can relate to—instead of saying ‘my bladder hurts,’ they can say ‘I’m having a lot of cramping today,’” Milspaw explains.

Egan says her daughter initially glossed over her issues with IC while talking with peers, but over time began sharing her experiences with friends. “The longer she had it, the more confidence she gained, and she felt more comfortable with it,” she says. “We just explained that it’s something you have to deal with, and you can handle letting people know or not know any way you want.”

Diagnosed with IC at 16, Amanda O’Connor ultimately wound up telling her high school friends about the condition, but she had a little help. Her best friend’s mother was a nurse, and the three of them initially discussed the condition together. Conversations with other friends followed later, and O’Connor paid close attention to their reactions. “I made sure I hung out with positive people,” she says.

As with all IC patients, diet can also be an issue—particularly given adolescents’ unpredictable schedules and activities. “Annie’s biggest culprit is pizza—what teenager doesn’t have pizza every week?” her mother asks. Parents can help their children track and manage their diet—one of the very many ways in which family support is critical.

“Every time she’d have severe pain, I was holding her up in the bathroom,” Egan says. “We gave her continual support—being there and encouraging her to figure this out, and just making sure she knew we were doing everything we could to alleviate her symptoms.”

As adolescents struggle to become the adults they want to be, it’s also critical that caring people help them separate their condition from their identity, according to Milspaw. “Expanding their definition of who they are and reminding them of all their other strengths and that they can have a voice in allowing how much this will define them is critical,” she says.

One strategy: focus on the upsides, including pointing out how having a condition like IC can foster empathy, help them relate to other people, and become stronger and more confident in ways they might not have otherwise, according to Milspaw.

“Talk to them about how navigating this condition can help them in what they want to do,” she says.

## ANNIE EGAN

Diagnosed with IC as she was beginning her freshman year of high school in suburban Chicago, Annie Egan didn’t slow down.

Despite her struggle with abdominal pain, tightness, and frequent urination, Egan stuck with her two favorite sports—softball and competitive cheer—throughout high school. She also volunteered, remained active in school events, and traveled extensively with family. A combination of medication and diet helped Annie manage her symptoms, but her mother, Jean, believes that the whirlwind of activity also helped her focus on things other than being sick.

“I thought to myself this poor child doesn’t have a minute of time to herself,” Egan says. “Then I realized maybe she keeps herself busy to not think about her pain.”

Annie, who turned 18 in May, graduated high school this spring with a 4.7 GPA. She will attend Northwestern University in the fall.

“I believe her being extremely busy and constantly moving was a good thing for her,” Egan says.



# YOUNG ADULTS

Whether attending college or not, young adults face unprecedented freedom. With a condition like IC, that freedom can be both a blessing and a curse, according to Milspaw.

“Because you don’t have that set schedule any more, you’re more able to keep your experiences private,” she says. “The con to that is that it’s also easier to isolate yourself, and it takes longer for someone to notice.”

For Amanda O’Connor, IC made the decision to attend a residential college more challenging. “As a freshman, not only do you have to worry about fitting in and wondering what you’re going to do and living in a dorm for the first time, the illness made it a lot worse,” she says.

O’Connor found support from multiple sources on campus, including counselors and a mindfulness group (see profile, below). She learned strategies ranging from writing in a journal and drawing when she was in pain to controlled breathing exercises. “These strategies seemed to really help a lot,” she says.

Fighting the tendency towards isolation often requires moving past “all-or-nothing thinking,” Milspaw says. Instead of committing to attending an entire football game or party, people can break events into smaller pieces and give themselves permission to leave early if needed. Other strategies include developing a contingency plan in case a flare occurs during a social event. “That helps empower them and feel more in control,” she says. “Sometimes it even calms them enough that they won’t have a flare.”

As in high school, managing relationships with peers is also challenging in college. With pain medication making it difficult to study during flares, O’Connor admits that it was difficult at times to empathize with her friends. “They would complain—I have so much to study, so much work to do, and I felt like I had to study whenever I was healthy because I couldn’t when I was in pain,” she says. Feeling

sick and financial constraints also limited her ability to do extracurricular activities and take mission trips. Ultimately, “I learned that everybody’s different and has their own way of dealing with their struggles,” she says. “I realized I shouldn’t be judging them.”

It wasn’t until graduate school that O’Connor also realized the importance of acknowledging the need to scale back when her IC got worse. As an undergrad, when she tried to ignore an uptick in symptoms, she found herself in the bathroom more often, or at times, too sick to even attend class. “It took me a really long time to realize that it’s okay to take breaks and lie in bed all day and give yourself time to heal,” she says. “If you don’t, it will come back to hurt you.”

Young adulthood is also a time when relationships and sexuality continue to mature, and IC poses additional physical and psychological challenges. According to Milspaw’s own research, there’s a strong correlation between IC and sexual pain—as many as 80 percent of patients have both. “Sexual relationships between peers can add a lot of confusion, low self-confidence, and insecurities,” she says. “People wonder who’s going to fall in love with them if they have a chronic illness. They say, ‘I’m already broken.’”

But with youth comes one potential bright spot—a more open mindset to exploring sexuality in different ways, allowing IC patients to reframe intimacy in ways that work for them. While it’s dangerous to generalize across every individual in an age group, Milspaw points out that younger people often more readily rethink intimacy than their older counterparts. “It’s harder to teach old dogs new tricks,” she says.



## AMANDA O’CONNOR

For Amanda O’Connor, a lecture in a human development class at North Dakota State University was an important moment that helped her find a path through college while struggling with IC.

“They stressed that taking care of yourself is really important, because it’s critical if you’re going to take care of others,” says the North Dakota grad student, now 25. “With an illness like IC, it would be devastating if you don’t practice that. It set a good example.”

Diagnosed with IC when she turned 16, O’Connor graduated early from high school and attended NDSU. While she had to go to the bathroom as often as 40 times a day, she credits the university for emphasizing self-care both in and out of class. As a freshman, she saw a counselor to help navigate the new college experience while dealing with frequent urination and pain. Later, a campus mindfulness group recommended by a friend helped her manage pain and stress. Prayer and the support of her family and friends also helped O’Connor navigate college.

Now in graduate school, O’Connor ultimately managed to improve her symptoms with an Interstim implant, although she has since also been diagnosed with Postural Orthostatic Tachycardia Syndrome (POTS), a condition that causes the heart to race when standing. Given her experiences, O’Connor hopes to become a counselor and support others with IC and similar conditions.

“I want to help couples who wind up having a chronic condition because it changes so much in the relationship when you’re dealing with such horrible illnesses,” she says.





# PRIME OF LIFE

Children, career, family—these are the things that drive us during the prime of our lives. Add IC to the mix, and it often can feel like something has to give.

That was definitely the case for mother of two Erica Welu, whose children were five and eight when she was diagnosed at 36 (see profile, below). “I had to get my kids off to preschool in the morning even if I was having a bad morning,” she says. “You’ve got to do what you’ve got to do.”

One way to navigate these conflicting demands is to make accommodations—but not make do.

“It’s all about flexibility and how they define being flexible,” Milspaw explains. For parents, that can involve rethinking how they interact with their children “without running around the park” when flares surge. In work settings, that can involve identifying career goals and brainstorming new ways of reaching them, she says.

“You have to expand the definition of success in any role and find out how to give yourself permission to adapt to that,” Milspaw says.

Welu took ownership of her IC by reading and sharing. “I did a lot of reading, and that helped me feel more in control of things,” she says. “And I was never quiet about it—I would tell anybody who would listen that I have this bladder disease that’s incurable, and this is what I was going to do about it.”

Support from family and friends also becomes hugely important. “All my girl friends know I don’t want to see

them drinking a pop in my presence,” Welu says. “I’ll tell any of them that will listen that it could destroy your bladder. Everybody’s been very good about putting up with my strict dietary rules.”

## DAVE ALEY

Dave Aley lived with IC symptoms for a quarter-century before being diagnosed at 44. As a result, it took the benefit of hindsight to realize how much the condition had impacted his life.

“I hadn’t realized how much I was planning my life around going to the bathroom 20 times a day,” says the New Mexico mechanical engineer. “Once I was the guy who wasn’t ducking out of the meeting to go to the bathroom, I realized that it was bigger than being uncomfortable and having a lot of urgency.”

Told he had a small bladder through much of his adult life, Aley acknowledges his condition made him reluctant to pursue some work opportunities. He credits his relatively minor symptoms and participation in online support groups to maintaining a sense of perspective. Also important: “keeping doing things that are fun,” he says. For Aley, that means flying hot-air balloons whenever he can.

“Having hobbies that allow me to do things with a lot of positive people has been a good outlet,” he says.



Parents with chronic conditions with a genetic component like IC must also confront other concerns. “Right now things look good, but it’s a weird feeling to be a parent and

have a chronic disease that’s so painful and all-consuming,” Welu says. “It’s definitely a stressor—I have to remind myself, calm down, don’t freak out.” Support groups for kids and parents with chronic conditions could help, Welu argues.

Welu acknowledges she has had the comparative luxury of being a stay-at-home mom. Others have had to struggle with career challenges as the result of their IC.

Diagnosed with IC two years ago after a lifetime of symptoms, 46-year-old Dave Aley has only recently come to realize the impact the condition has had on his career (see profile, above). A mechanical engineer, he turned down an opportunity to work in a remote part of Canada because he wondered if “I could be out there

## ERICA WELU

When Erica Welu was diagnosed with IC in 2006, it was the answer to questions about the more than 100 bladder infections she’d had in her life. But as the mother of two children, the diagnosis also raised new questions.

Struggling to balance family responsibilities while seeking treatment for the condition was challenging, at times leaving the South Dakota mother angry and frustrated with the medical community, she says. But ultimately, she found effective treatment, beginning with a bladder instillation and following up with medication and other treatments.

“It took me a while to get to that point,” she says. “For a long time, I was bitter, and I blamed the food and the water and the medicines I’d been taking for other things. I kept trying to find a reason and figure it out on my own. Now I try to be open to going new routes by reading anything new that’s coming up—I fight things by being informed.”

As a parent, though, Welu worries about the impact the condition has had on her children. “I do wonder about the effect a parent with a chronic illness would have on a kid’s mental health,” Welu says. “As a parent with IC and kids, I think about it.” But she and others have pointed to possible upsides: “Maybe it makes them tougher—more empathetic,” she says.





without having to run off in the bushes every hour with this stupid tiny bladder,” he says. But as his symptoms grew worse over time, he found a job that offers enough flexibility to allow him to take a day off or leave early for an instillation when his IC flares. “I’m fortunate that I’ve ended up in a job situation with a lot of flexibility,” he says.

F. Neal Thompson was less fortunate. Diagnosed with IC when he was in his late 30s and in the prime of his career, the Virginia financial consultant found himself turning down opportunities to work and meet with clients out of town (see profile, p. 10). “Your tether becomes much shorter,” he says. “It’s hard to work a 9-5 job because you’re up all night. When I was doing a lot of work up in D.C., if I got caught in a traffic jam, there was no place to go to the bathroom. So you avoid those situations and withdraw.”

Thompson, like others, made changes to his lifestyle—scaling back his work duties and working from home. “You’re up peeing in the middle of the night anyway, you might as well be at the computer,” he says. He also became an expert on public restrooms around his home city of Richmond, Virginia, and learned to avoid traffic jams.

“You modify your lifestyle, and you hope people are receptive to that,” he says.

Through his time on the ICA Board of Directors, Thompson has seen the impact on career-age adults at a much larger scale. “We had doctors and lawyers who had to limit their practice, cut back, retire, or just slow down,” he says. “These are qualified, educated people who can make a contribution to society but can’t give it 100 percent. That’s the productivity we lose in this country because of IC.”

For women, menopause can mark the beginning of significant changes in their IC and its symptoms. But for all IC sufferers, the transition to the golden years can be frustrating, even frightening—particularly when it comes to thinking about retirement and uncertainty about the future.

When IC makes long-cherished goals like travel difficult for physical or financial reasons, “there can be a loss of their dreams of what retirement is going to look like,” Milspaw says. These limitations impact not only the person with IC, but also their spouse. “They’re not only feeling let down personally, but also that they’ve let their partner down in some way.”

Milspaw encourages people to grieve the loss of their dreams—in part, because doing so paves the way to “imagine what else is possible.”

“Going through the grief process is really important, because if you don’t, there’s going to be a lot of resistance to even imagining,” she says. After mourning the loss of their original dreams, people can think through what is and isn’t possible and begin the search for new goals. “It can be everything you want, but the details are different—not sailing around the world, but doing short little day trips can still achieve the overall goal they’re seeking,” she adds.

For women, menopause can either mitigate or exacerbate physical symptoms. “In someone with IC prior to menopause, they usually see the calming down of the flares post-menopause so long as there aren’t other variables,” Milspaw says. “If you see the onset of IC after menopause, hormones may or may not play a role.”

For some, menopause can trigger additional complications. For Jann McGaughey, estrogen depletion led to vulvodynia about a decade after first being diagnosed with IC, which contributed to a worsening of her symptoms (see profile, left). The silver lining was that treating the vulvodynia with estrogen suppositories wound up mitigating other bladder symptoms for McGaughey.

“Once I got rid of that complication, things started



## JANN MCGAUGHEY

Jann McGaughey always needed to go to the bathroom more often than her friends. “The joke was Jann knows where the bathroom is,” she says.

But as she approached 50, McGaughey’s lifelong issue with frequency became worse. “I was pretty comfortable in my own skin, but it was getting more and more frequent to the point where it affected my life and I couldn’t do things,” says the Texas resident, now 73.

Ultimately diagnosed with IC a few years later, McGaughey’s symptoms grew worse after menopause. Treating the resulting vulvodynia, as well as changes to her medications and the use of

Interstim therapy, ultimately brought her to remission about seven years ago. That’s led her to resume the activities she once had to scale back, including travel.

“I still have periods of frequency, but there are very few things that I won’t do,” she says.

McGaughey urges others to not lose hope in the face of IC. “I’m the kind of person that the more I know, the better I do,” she says. “I try to tell people who might have IC to try everything they can, and try to live as normally as they can. I was not going to let my condition leave me at home.”

## F. NEAL THOMPSON

After struggling with a severe case of IC for more than 35 years, F. Neal Thompson finds some dark humor in the fact that his symptoms subsided as he entered his 70s.



“When I talk to my elderly friends, they have prostate problems and are going to the bathroom more than I am,” jokes the 75-year-old Virginia financial consultant.

Thompson was diagnosed with IC in his late 30s, and his symptoms grew progressively worse. In response, he scaled back his career, working from home and limiting travel. Investment income supported his reduced income and costs of treatment until he shifted to more of a “retirement mode” in recent years, which was followed by significant improvement of his symptoms. He still serves as a lieutenant colonel in the National Guard auxiliary and, as a member of ICA’s Board of Directors, has become a tireless advocate for IC research.

“It’s an uplifting thing to spend time with people with the disease,” he says. “We share the most intimate details of our lives because we share the same tragic condition.”

At the same time, Thompson points to humor as another key to coping with the condition. “It helps not to take yourself or your condition too seriously,” he says. “Force yourself to get beyond the IC and focus on the positives in your life.”

falling into place to achieve a very nice remission,” she says.

Even in cases where physical complications don’t arise, the emotional toll of menopause can pose an additional burden. “I’m usually a pretty calm person, but if I started to talk about IC with a close friend, I would start crying,” McGaughey says. “A lot of it is how your emotions are because of menopause, but in different stages of your life, you can lose confidence in yourself, and that just made things a lot harder.”

Common among many seniors, that loss of confidence ties into broader worries about the future older people face, including the difficult question of what will happen when

they’re physically incapable of taking care of themselves.

“You have those life issues to begin with, and when you have something like IC that is still not universally understood or managed appropriately, it’s just going to increase their fear of not being taken care of,” Milspaw says.

McGaughey serves as a hospice volunteer and visits nursing homes, so she knows this very well. “It makes me empathize with people in that condition,” she says of seeing nursing home residents in bed awaiting clean sheets.

Older IC patients often hold out hope for something else—an end to their suffering and that of others. “I hope I live long enough to see a cure,” Thompson says. “I’d like to live long enough to see some inroads.”

## LIFE PLANNING

Like the physical symptoms of IC, each person with the condition is unique. As such, generalizations about age and stage of life may or may not apply to everyone. However, there are some common things any patient with IC should keep in mind as they navigate challenging times, according to Milspaw.

First is to find ways to have fun, no matter what the circumstance. “Play can be such an amazing stress reducer, as well as calming the nervous system and reminding people they can have fun in a number of ways even if they can’t use their body the way they want to,” Milspaw says.

Another is to avoid all-or-nothing thinking, she adds. “IC

# Find ways to have fun, no matter what the circumstance.

is something that will ebb and flow, and you might have to be flexible with your plans or have some backup plans—which is important to do anyway.”

*Mark Toner is editor of ICA Update.*