Feeling down about RA?

When Kelly Young was diagnosed with rheumatoid arthritis (RA) at age 40, her first concern was for her five children, especially her 6-month-old son: “How will I be able to take care of my baby if I can’t even get his shoes on and off?” she remembers telling her doctor. “I was shocked by what I couldn’t do suddenly, like pull the sheets off the bed or raise my arms up to do my hair.”

Since then, Kelly, now 48, has learned to navigate not only the unpredictable nature of RA, but also the strong emotions it stirs up.

“It’s a lot of confusion that strikes in the prime of life when people are working on their career and raising a family,” says Kelly, noting that RA often occurs between ages 20 and 50. “You might have fear or guilt or anxiety. You feel alone in your struggle because people don’t understand the disease.”

If that strikes a chord, here’s what Kelly wants you to know: “How you feel right now is not how it will stay. Every day won’t be as hard as today. There are going to be better days.” These strategies can help make that happen:

Unload your worries.
“Don’t feel you’re stuck with the pain. Controlling it can help you cope better emotionally,” notes Kelly, who takes nonsteroidal anti-inflammatories as needed. “It’s okay to ask for help.” As a homeschooling mother of five, Kelly knows how hard this can be, especially for parents. “We feel bad when we can’t do it all, but you have to give yourself permission to get help. I’ve even gotten gifts from my mom to get a housecleaner,” says Kelly gratefully.

Expert tip: Consider what someone is good at and ask for a hand in that area, suggests New-Orleans based rheumatologist Madelaine Feldman, MD. For example, after Tara Manriquez of Vancouver, WA, was diagnosed with RA, she enlisted her husband, Jaime, to adapt the household to her needs. “Thanks to his Air Force career, he’s great at finding technological solutions,” she says, like helping Tara avoid hand pain by replacing doorknobs with levers and finding a garden hose with a special, easy-grip attachment.

Expert tip: If your meds aren’t working, ask your doctor if changing the dosage or timing might work, suggests rheumatologist Elinor Mody, MD, of Brigham and Women’s Hospital in Boston. For example, taking your medication as soon as you wake up might lessen pain later in the day. Likewise, taking certain anti-inflammatories (such as prednisone) at night could interfere with restful sleep, which is crucial to controlling pain.

Stay ahead of pain.
“Don’t feel you’re stuck with the pain. Controlling it can help you cope better emotionally,” notes Kelly, who takes nonsteroidal anti-inflammatories as needed. “How you feel right now is not how it will stay. Every day won’t be as hard as today. There are going to be better days.” These strategies can help make that happen:

Get understanding
Find support online or in person, says Kelly, who works with Arthritis Introspective, a group that connects RA patients with community programs (ArthritisIntrospective.org). No local RA group? “Find someone through your doctor’s office,” she suggests. “If you can find just one person to meet for coffee, that’s a good start.” Or take advantage of social media: “I know two women in Oregon who met and wanted to find others with RA in their area. They started a Facebook page and now know about 20 other women.”

Learn all you can.
Information is your greatest ally to help educate and empower others who have the autoimmune disease, says Kelly, who founded RAWarrior.com and the Rheumatoid Patient Foundation (Rheum4US.org). “So many people don’t realize that RA is not just arthritis—it’s not just your joints. It can affect the eyes, heart, lungs—the whole body.” In fact, her foundation launched a campaign to promote “Rheumatoid Disease Awareness” to distinguish it from other types of arthritis.

Expert tip: Help your family become educated, too, says Dr. Feldman. “Many times a patient’s family doesn’t realize how sick their family member is because their joints are not always swollen. There’s more than the eye can see with this disease.” She suggests bringing family members to an appointment (alert the office ahead of time) so they can be involved in your care.

Cultivate a fighting spirit.
“Keep fighting to get the care you need,” stresses Kelly, who remains hopeful about the new RA medication she recently started. “It takes courage to fight RA. I always tell people to never, ever give up.”

—Larry Murray

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