LIVE on the Move

Jennifer Hartley recalls the pain of being reminded she was different from her peers.

Brian Quinn remembers his surprise and shock as he was rushed into emergency surgery.

Sheila Hayes still reflects on the life on which she almost missed out.

All three have had medical conditions they feared could prevent them from leading healthy lives. At different points, they also felt the fear of not having any future at all.

When a teen is afflicted with a life-threatening illness, the problems go many levels beyond pimples and prom dates. Like it or not, these adolescents end up with different lifestyles than the rest of their classmates.

Stacey McMail pointed out that seriously ill teens endure emotional trauma along with physical rigors. For this reason, she said, other teens should handle these situations with sensitivity.

"Kids have a tendency to ostracize—to make patients stand out by whispering behind their backs, 'Oh, my gosh, what happened to Sandy?'" said McMail, the coordinator of social work at St. Joseph's Hospital in Elmira. "It's important that the relationship stays the same, that the patient isn't treated any differently than before."

For example, if a teen walks down the school hallway with a shaved head due to cancer treatments, the best tactic is to address the issue directly.

"It's important that they ask the patient what happened. This gives them an opportunity not only to find out what's going on, but also what the patient is feeling. It opens up a line of communication," McMail said.

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Story by Mike Latona

In the paragraphs below, Jennifer, Brian and Sheila share how they have dealt both privately and publicly with their afflictions.

Jennifer Hartley realizes her future is uncertain.

"People would come and stare at me," Jennifer said of the schoolmates who wondered why she didn't participate in gym class.

Jennifer, who turned 15 this week, is already 6 feet 1 inch tall. But her physical activity is extremely limited because she suffers from Marfan syndrome.

This syndrome is a disorder of connective tissue. Jennifer's condition is evidenced not only by her height, but internal deterioration of her joints, bones and internal organs.

The most hazardous aspect of Jennifer's illness involves her aorta, the artery that carries blood from her heart and eventually to the rest of her body. Jennifer's aorta will continually expand as she gets older, leading to heart complications that might cause her to die before the age of 40.

Jennifer's mother, Mary Lynn, 39, has survived longer than any other family member with this hereditary syndrome. Her uncle died at 34, and her grandmother at 37. Jennifer's 13-year-old sister, Tracy, also suffers from Marfan syndrome.

Because most of Jennifer's difficulties are internal, she has trouble convincing others how serious her condition is.

"If I ended up explaining why I can't play basketball, I'd end up talking the whole day," said Jennifer, a parishioner at St. Mary of the Lake Church in Watkins Glen.

Jennifer underwent surgery on her spine in March. Her body is now filled with so many metal rods and screws that even a minor fall could send her right back to the hospital.

"I feel like this really expensive toolbox," Jennifer joked.

Despite her dilemma, Jennifer is optimistic that a cure for Marfan syndrome will be discovered within the next few years.

"That's something I'm looking forward to," Jennifer said. "If God wanted me to live longer, I'm going to go on as he intended me to. If h
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