

Stephen ministers learn 'to walk into the mystery of another'

By Teresa A. Parsons

Lying in a hospital bed amid a tangle of tubes and needles, David Riley is getting ready to die.

He's not giving up by any means. No one who wasn't a fighter would have survived till the age of 18 with Duchenne's Muscular Dystrophy. One of the most common forms of the disease, Duchenne's nearly always kills its victims by the time they reach the age of 15.

But with each battle he wins, David is reminded of his mortality, and as an intelligent adult trapped inside a fragile and weakening body, he has an awful lot of time to think about death.

As he struggled to recover from a bout of pneumonia recently at Wilson Memorial Hospital in Johnson City, N.Y., David's questions to his parents, Sharon and Jim Riley, reflected those thoughts.

"He asked me why we let them put him on a respirator this time?" Sharon said. "He's never asked me anything like that before ... he knows his time is limited."

"He's worried about dying and going to hell," his father added incredulously. "It's been a big thing over the last few months ... He thinks back to when he was little and to dumb things — like when he fought with his brother. He wants to be reassured that he's been a good person."

David is the Rileys' second son to fall victim to Duchenne's Muscular Dystrophy, a hereditary form of the disease that has been incurable to date. Their older son, Jimmy, died three years ago. Unlike other forms of muscular dystrophy, which generally develop in adults and are seldom fatal, Duchenne's affects male children, becoming apparent by the age of three or four.

Because their muscle tissue degenerates rapidly, victims are usually confined to wheelchairs by early adolescence. As the joint muscles continue to contract, they cause curvature of the spine, which, in turn, reduces lung capacity and leaves the victim vulnerable to respiratory infections.

If experience hasn't made their ordeal any easier, the Rileys say their Stephen Ministers — Mary Ann Cascarino and Mary Federowicz — have.

Cascarino and Federowicz are two of more than 20 parishioners at St. Margaret Mary Parish in Apalachin who are learning to minister to fellow parishioners and neighbors who are struggling or suffering, whether in a time of crisis or from long-term illness or disability. Participants in the program, known as Stephen Ministry, attend 30 training sessions and commit themselves to two years of service, according to Nancy Chapura, the parish's Stephen Ministry coordinator.

Although the Rileys say they've been blessed with a wealth of supportive friends over the years, David can never have too many visitors, and his parents can never have



Visits from Mary Ann Cascarino, a Stephen Minister, distract 18-year-old David Riley from the hospital routine.

Jeff Goulding/Courier-Journal

too many listeners. And because they're trained, Stephen Ministers are better prepared than average — at least theoretically — for the kinds of tough questions David is asking.

Because his parents spend so much time with David, they appreciate having an "outside" appraisal of his condition, his fears and concerns. "We're so close to him (that) it's tough to see what's important sometimes," explained his father, Jim. "These people are a step back. He can talk to them better about some things than he can to us."

"It really gives David a shot in the arm to have young people come in," Jim added. "He's interested in all the same things any 18-year-old is ... it gives him something to look forward to."

Stephen Ministry was introduced to the Southern Tier three years ago by a couple from Chemung County. At the time, the parish staff at St. Margaret Mary considered it, but "put it on the back burner," Chapura recalled.

When Father David Simon, pastor of St. Margaret Mary, was reintroduced to the program last summer, he agreed that the time was right to put the program together. He, Chapura and another parishioner attended a training seminar at the University of Baltimore in July and began parish training

sessions in September, 1985.

Chapura, who comes to the parish with a background in social work, also handles the parish's family services and crisis intervention. Although she found the adjustment to working with volunteers a challenge, she has been impressed by the dedication of the Stephen Ministers. "They are a very committed group," she said. "They're enthused and they let you know it."

Chapura runs most of the training sessions, with the exception of an occasional guest speaker. Father Simon also handles a session now and then, and has become even more convinced of the program's value.

"We must equip lay people for ministry. I'm here alone, but this would be necessary even if there weren't a shortage (of priests). It is the right and the duty of the laity to minister," he explained.

"I like Stephen Ministry because it's very upfront about being a ministry that incorporates spirituality with caring and helping another person."

In their weekly, two-hour training sessions, for instance, Stephen Ministers act out situations where they ask to pray with people — from those who've suffered a death in their family to those who are simply lonely.

"Don't pray a prayer that's a solution to the situation," Father Simon cautioned in a

recent session. "Too often that turns into a mini-sermon. Make it an enabling prayer instead."

He stressed the importance of making some physical contact with the person as early in a visit as possible — to hold a hand or make the sign of the cross on a forehead. He also urged the group not to be uncomfortable with silence, noting that "silence is a wonderful prayer."

"It's OK to be human, to cry or be upset, to ask God for help (with what to say)," he concluded. "Everyone wants intimacy, to walk into the mystery of another."

For the first 15 weeks, Stephen Ministers are involved with training only. Topics include listening and telephone skills, assertiveness, making the first helping contact, and the importance of confidentiality.

Then, halfway through the course, they are assigned to "cases" — people who have contacted Chapura and agreed to accept a Stephen Minister. So far, there has been no shortage of people willing to accept them in the Apalachin area. In fact, there's a waiting list.

Mary Federowicz, 15, has been ministering to David Riley now for several weeks. "I did it because I like working with people," she said.

When she met David, he had already been admitted to the hospital. "I was scared right at first by all the machines," she recalled, "but I just started talking to him, and gradually he started opening up. Each time I learn a little bit more about what interests him."

Federowicz hasn't yet talked about dying with David. "I think it's up to him to bring it up," she said. "If he does, we'll talk about it."

David's parents, on the other hand, have frequently spoken about his fear of dying with Mary Ann Cascarino, their Stephen Minister.

"I think part of the problem is that he's responding so differently from their other son," Cascarino said. "I really don't know how to respond yet."

"Right now I'm doing a lot of listening," she added. "I volunteered out of a desire to help somebody if at all possible. But you don't really know if you're helping a lot of the time."

Like Federowicz, she, too, was fearful and uncertain at first. "I just took a deep breath and said: 'God, it's in your hands,'" she recalled.

Beyond assisting in a practical sense, that's all Cascarino and Federowicz or any Stephen Minister can do — listen to the people they visit and join them in placing their pain or fear before God.

Sharon and Jim Riley are equally powerless to do much except watch and support David in his physical and emotional struggle.

"I wonder if this is what God goes through with us?" his mother said.

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Continued from Page 7

them living in desperate conditions.

Returning to the U.S., Sister Darlene visited her parents' home, where she became seriously ill. While recuperating, she became involved with local inter-faith task forces on Central America and refugees.

"I found 15 Guatemalan men living in one motel room in a suburb of Phoenix," she recalled. She also found people picking crops and not earning enough to buy food or necessary medical attention, and she began to help. Not until several months later did she learn that what she was doing was considered against the law.

"I prayed and thought about it," she said, "but there was no way I could turn my back on them. There are very few people who understand as I did why they are here."

Although she remains optimistic about the jury's eventual verdict, Sister Darlene has also realized she could serve time in prison. "I thought a lot about it this summer and I guess I became reconciled to it, as much as anyone can be," she said. "But I've been too involved in the case for the past four months to give it much attention."

Should she be acquitted, Sister Darlene said she would continue her commitment to peace and justice for Central American refugees.

"Once you start down this road you can't turn back. The road only grows narrower and I'm not sure where it's leading me," she said. "There have been times when I wished I could go back to being the person I was before. It was more comfortable."

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