

Suburban Life

Loraine McClish editor / 477-5450



(F) 18

Research critical in serious illness

By Rebecca Haynes
staff writer

UNDERSTANDING THE MEDICAL lingo and being able to ask the proper questions are among the top pieces of advice Lydia Cunningham has to offer in her new-found role as a patient advocate.

"Before you can take control of a situation you have to understand what's going on," said the Bloomfield Township resident, who was forced to learn to make her way through the medical red tape when her husband was critically ill.

"The best way to start is with literature specifically written for the lay person, stuff you can find in the public libraries."

Many libraries carry health encyclopedias that give basic descriptions of most illnesses, their symptoms and methods of treatment. Sometimes these books can even be found in the children's section, Cunningham said.

A library's magazine index will list all of the articles on a particular subject written in the popular magazines. A newspaper index will list the same for newspapers. These methods can be helpful to the lay person.

"PEOPLE CAN also call organizations involved with the particular disease they're trying to learn about," Cunningham said. "Some of the more common groups can be found in the telephone book."

For those that aren't, a health information center hot line can refer callers to any of 1,000 appropriate

hot lines, federal agencies or private organizations.

The center also offers bibliographies of health materials, resource lists on financing health care and a directory of federal health agencies, Cunningham said. Its number is 1-800-336-4797.

By doing this basic research a person will obtain a working knowledge of the medical language and the illness they face, Cunningham said.

Once this groundwork has been laid, the researchers can then move on to medical school libraries, which are open to the public. Local residents can use the libraries at the University of Michigan School of Medicine or the Wayne State University School of Medicine.

Hospital libraries are another information source. They are usually open to hospital patients and their families or to the public with a doctor's authorization.

TEXTBOOKS WILL contain gen-

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eral information, Cunningham said, but the medical journals will hold articles on the latest treatments.

The Index Medicus, updated monthly, is a guide to finding these journal articles. However, before it can be used the researchers must know the formal medical term for the illness or treatment for which they're looking.

The index then will list names of articles, who wrote them and where that person is from. It's up to the researchers to figure out which ones they may need to read, Cunningham said.

A new MEDLINE computer search will scan Index Medicus for you, but there is a charge, usually around \$25, and it must be done through a librarian.

"This isn't a two-hour process. It's a lot of work. But you can get a lot further if you're able to talk to the physician more on his or her level," Cunningham said.

Please turn to Page 2



STEPHEN CANTRELL/staff photographer

Lydia Cunningham has become an advocate for others after acting in the same role for her husband, Joe, when he was diagnosed as having terminal brain cancer. Since that time she has received more than 100 calls for help from around the country.

Advocate

Bloomfield woman offers help through the world of medicine

By Rebecca Haynes
staff writer

ACLOSE CALL with her husband's near death has turned a Bloomfield Township woman into an advocate for others suddenly thrust into an unfamiliar medical world.

Lydia Cunningham was forced to quickly learn everything she could about how to get the answers she needed after her husband was diagnosed as having an inoperable, malignant brain tumor more than three years ago.

Because of her persistence and determination, Joseph Cunningham is alive and well today and expected to live a long, full life. Although they both remember the experience as extremely traumatic and difficult, both say they weren't expecting to have to fight their way through a medical system which could at times seem almost unwilling to help them find the answers for which they were searching.

"When Joe was diagnosed I decided I would educate myself so that I could talk to the doctors," Lydia said. "I found out about an experimental type of laser surgery being done at the Mayo Clinic that seemed appropriate, but his doctors told us it wouldn't work for him and to stick with the traditional treatment."

THAT TRADITIONAL treatment would have involved surgically removing as much of the tumor as possible, a treatment which Lydia says does not have a very high success rate.

Because she continued to ask questions and was bold enough to call the surgeon at the Mayo Clinic, she discovered this new treatment could be very effective for her husband's tumor. They took the next plane to Minnesota and the gamble paid off.

"I knew that if I sat by and did nothing he was going to die," she said. "I thought to myself how could I look at my children if that happened and I hadn't done anything to try and stop it."

"This experience taught me that doctors don't always know the latest procedures that are going on in other states," Lydia said. "Everything changes so rapidly and there are so many medical journals that it's very difficult for doctors to read everything, and even if they do know, they're real reluctant to recommend experimental treatment in another state."

Malpractice, she said, is defined by whether a physician met standard practice procedures for their community, so if a physician doesn't refer a patient for experimental treatment elsewhere, it's not considered malpractice.

HER EXPERIENCES prompted Lydia to write an article which was published in Woman's Day magazine and from that point on a new career had begun. She began receiving letters from people who were in similar situations and didn't know where to turn for help. Lydia's role of patient advocate for her husband had begun to turn into advocate for many other patients and families both nearby and across the country.

To date she's received more than 100 phone calls for help from people facing all different types of illnesses. Often she responds by giving the names of organizations where that person can obtain more information or by telling the person how to do research and sometimes even helping with that research herself.

Kathy Wiseman of Livonia was one of those who called Lydia for help. Her husband, Tim, was diagnosed a year ago as having an inoperable brain tumor and neither could believe there was nothing that could be done.

"They were saying this to a 30-year-old man who hadn't even been feeling sick and never missed a day of work," Kathy said. "A friend showed me the Woman's Day article Lydia had written, so I contacted the magazine and they of course told me

Please turn to Page 2

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