

Stanford Hospital Health Notes

special feature

A community health education series from Stanford Hospital & Clinics

Support Groups Supply Crucial Help

Sharing and learning for healing

Even before her weight loss surgery at Stanford Hospital & Clinics, Clare Sisto was reassured that her physician, John Morton, would prescribe more for her than an operation. He asked her to go to an informational support group meeting before her surgery – and also to a post-op support group meeting, one designed to be a vital and secure platform to manage the big life changes that come with the surgery. Cisto already knew that those changes wouldn't be easy.

“We all had a story to share – and we all really want to help each other and be successful.”

— Clare Sisto, Stanford Hospital & Clinics weight loss patient

At the pre-op meeting, patients receive valuable factual information from Morton, plastic surgeons and a nutritionist. Dana Schroeder is also there and introduces herself as the facilitator for the post-op group, the one that Morton knows is a crucial part of the surgery's success. When Schroeder tells the group that she went through the surgery several years ago, there is a gasp of admiration from the group.

Doctors can physically change someone's stomach, but the patient needs to make big life changes around what kind and how much food to eat – and then maintain them. “It's not an easy thing,” Morton said. “It's not easy at

all.” And it's important, he said, to know you're not alone.

At Stanford Hospital & Clinics, patients and their families can find many support groups, made possible by a firm belief and commitment to the idea that these groups are an essential and effective part of therapeutic treatment for many diseases and conditions, whether cancer, infertility or stroke. The Hospital has also gone one more important step farther, creating supportive care groups for patients' caregivers, in recognition of the valuable role they play.

The proven power of support

Morton patient Clare Sisto went to the support meetings at the Hospital “just to be part of the program,” she said. That changed quickly, however. “I wanted to go,” she said. “I wanted to participate. I wanted to be with other people who had experienced the surgery. We all had a story to share – and we all really want to help each other and be successful.”

The American tradition of people with similar issues gathering together to educate and support



Before her weight loss surgery, Anjanette DeVito wouldn't have been able to walk her dog, Scooter. Now, with the help of support group, she has lost weight and kept it off.

people who don't need to have anything explained. In the Stanford weight-loss surgery support group, Sisto said, she found that comfort. “I felt like they understood. Nobody understands like they do,” she said. “You feel a camaraderie with them – they share something you share, that even your best friend doesn't know what it's like.”

In the group's shelter of acceptance, Sisto felt free to vent about many things, including people's attitudes toward those with a lot of extra weight.

The group also serves as a backstop of accountability. One member told the group about “how she was eating all

each other through difficult times is one that dates back to the 18th century.

“You don't need to have a randomized trial to tell you that a parachute is helpful when you jump out of a plane,” Morton said. “We all accept support groups as a good thing.”

“Surgery is a tool, not the answer. If you don't fix your head, you won't fix anything.”

— Anjanette DeVito, Stanford Hospital & Clinics weight loss patient

Two years after her first weight loss support meeting, Sisto has lost 120 pounds and the group is a continuing companion of her journey. Losing the weight, she said, “doesn't mean the baggage goes away. It takes mental and physical work.” And the group is there for her when she's having a bad time. An hour with them, she said, and she can “walk away feeling good, and recognized.”

Acceptance and accountability

Transformation from one way of life to another is much easier with

this bad stuff. We kinda had this little network – one person agreed to call her a couple of times before the next meeting and she agreed that would be a good idea. We were all concerned about her.”

But some people want to do things for themselves – and resist going. Six months after her bariatric surgery at Stanford, Anjanette DeVito finally attended a meeting. She'd lost 100 pounds and “the stages of change were happening quickly,” she said. “I felt like I needed a lifeline. I had to reach out.” She had discovered that “surgery is a tool, not the answer. If you don't fix your head, you won't fix anything. I still struggle with emotional eating and find that if I have an outlet, I do better.”

A circle of understanding

When her mother died unexpectedly, DeVito might have gone back to eating as solace, but she turned to the group. “I knew it would pull me back,” she said. But occasionally, the group serves another purpose – it's a place where she can share freely her challenges without really needing specific advice. Just by verbalizing them, she said, “you take the mystery out of it, you take the fear out of it.”

FINDING SUPPORTIVE CARE AT STANFORD HOSPITAL & CLINICS

Call 650-725-9456 for more information about these groups:

- Brain Tumor Support Group
- Caregivers Workshop
- Colorectal Support Group
- Gynecological Cancer Support
- Group Support- all cancers
- Head & Neck Support
- Leukemia & Lymphoma Family Support
- Renewal & Recovery Breast Cancer Support

To participate in the Weight Loss support group, contact Dana Schroeder, (408) 307-2890.

For more information on the Caregiver Solid Organ Transplant Support Group, contact Rodney Plante, (650) 725-8636. For more information on other support groups available for transplant patients, call (650) 723-4000.

For more information about the stroke support group, call Pam Triano, (650) 498-7852.

The Stanford Health Library is a resource for more information about many other Hospital support groups. The library has three locations: G-2B Stanford Shopping Center (650) 725-8400; E303 Stanford Hospital (650) 725-8100; Stanford Comprehensive Cancer Center, 875 Blake Wilbur Dr. (650) 736-7157.

The Stanford Women's Health program runs support groups and special workshops. Contact Penny Donnelly, (650) 723-6408.



Jack and Lola Schaefer had shared a long life together before her lung transplant, but they are both grateful for the lessons Jack learned in the Solid Organ Transplant Caregivers Support Group.

feel like you're the only one,” said another group facilitator, social worker Jenny Kwak. “It's isolating.”

Lola Schaefer's husband, Jack, turned eagerly to the group. The Schaefers, long-time residents of Los Gatos, active and enthusiastic about life, had lived for several years with Lola's lung disease, idiopathic pulmonary fibrosis. In the last winter before her transplant, Lola, 68, went skiing just as always, even though she had to take her oxygen tank with her. Then the disease advanced so quickly her only hope was a transplant.

instinctive thing of taking care of someone.” In the comfort of the group, he could ask the difficult questions and “things you don't even think of” to ask, he said.

The group's common experiences also helped Jack Schaefer cross the hurdle of isolation. “Mentally you know there are others like yourself,” he said, “but it doesn't hit reality until you're sitting in the room – and you all have the same problem.”

He became more empathetic, he said, helped by greater understanding of what transplant patients go through. “Otherwise the only thing you have to measure anything by is how you do it,” said his wife. “Hearing others' experiences opens your eyes - he became a lot more patient.”

And in better understanding, he said, “a lot of stuff that might have been an issue five years ago, you just ignore it.”

His wife's transplant was almost two years ago, but Jack Schaefer still goes to the group, now more for others than for himself. “You try to give encouragement and support for others,” he said, “in a safe place to talk about stuff you wouldn't talk about to anybody else.”

Caregivers Need Support, Too

As plentiful as support groups are for many health conditions, one group is usually overlooked – the families and friends who provide very necessary support for transplant patients. Many are thrust into the role, completely unprepared for its strenuous emotional hardships and physical demands, both before and after surgery. That ongoing stress can lead to depression, burnout and post-traumatic stress disorder. And, out of concern for their loved ones, many caregivers bottle up their feelings, reluctant to show

anything other than unwavering strength and patience.

Stanford Hospital & Clinics has long provided support groups for caregivers. “Patients are inundated with care,” said Rodney Plante, one of the several Hospital social workers who lead the group. “Caregivers,” he said, “need a place where it's safe for them to have an emotional meltdown or an epiphany or a gripe session.” And the listeners are people who become friendly travelers on the same road. “You can

And for people who choose not to share news of their surgery with anyone other than their immediate family, the support group offers complete freedom of speech within the understanding circle of the group. Sometimes, said a patient who has kept her surgery private, food “calls your name so loudly,” like any addictive substance does. Then, having

the group to keep her from falling back into bad habits is where its support “comes into play,” she said. “I don't understand how people who don't get to have support groups get through a lot of the bad times.”

The support groups are so popular that the only complaint from members is that they don't meet

“Mentally you know there are others like yourself, but it doesn't hit reality until you're sitting in the room – and you all have the same problem.”

— Jack Schaefer, husband of a lung transplant patient

In the long pre-op interview, a social worker told Jack Schaefer about the caregivers support group. “I wanted to go to see what else there was to learn,” he said. And he was well aware that “being a male, you're lacking in that

often enough or for long enough. Space is the spoiler.” “We are busting at the seams,” said Rodney Plante, a social worker who coordinates one of the Hospital's support groups. When the Stanford Medicine Outpatient Center opens in Redwood City in 2009, it will be the new home for an expanded Center for Weight Loss Surgery.



Anjanette DeVito loves her dog, Scooter, but to help her through the challenges of weight loss surgery, she turned to a support group.



Weight loss support group facilitator Dana Schroeder (l.) consults with bariatric surgery program worker, Marisol Fernando (r.), about the next support group meeting.