



When Amy started going out without her wig in April, her girlfriends gave her new look a new name, “Ginger.” At first she was nervous about people’s reactions. “It’s that first trip to Kramer’s when you run into six different people” that she dreaded, she said.

Coping with diagnosis just start of journey

Hinsdale mom shares her experiences during the 18 months after she learned she had cancer

Story by Pamela Lannom • Photos by Jim Slonoff

“Real stories take time. We stopped telling stories when we started to lose that sort of time, pausing time, reflecting time, wondering time. Life rushes us along and few people are strong enough to stop it on their own. Most often, something unforeseen stops us and it is only then we have the time to take a seat at life’s kitchen table. To know our own story and to tell it. To listen to other people’s stories. To remember that the real world is made of just such stories.”

— Rachel Naomi Remen,
“Kitchen Table Wisdom”

In two weeks Amy Owens will celebrate her first year of being cancer-free. This is her story.

Discovery

A week before the Owens family left for spring break in Cabo San Lucas last year, Amy received a notice that she was due for her yearly mammogram.

“I set it on my desk and thought, ‘Oh, I’ll do it when I get back from vacation.’”

She never imagined that she would discover a lump on the far right side of her right breast while on the trip.

“It was the first night of our vacation and I put on a tank top for the first time in a long time,” she said. “I remember specifically because I will never forget that moment.”

She went to scratch an itch under her arm and felt a lump the size of a pingpong ball. She showed it to her

husband. He told her it was probably a cyst, but he wasn’t being honest.

“As much as I try and tell her that it’s a cyst, I knew,” Brian Sr. said. “I told her afterward I knew right then that it was not a little bump.”

Having the mammogram when she returned home was a horrible experience, Amy said.

“The radiologist, he was like a brick wall. He didn’t give me any inkling either way — just, ‘It looks pretty serious’ and that was it.”

Amy didn’t know how to interpret the news and wondered if she was going to die.

“I remember going into the bathroom and just sitting and crying because I didn’t know. I was so afraid. It was horrible.”

Waiting for results after the biopsy was no easier.

“You’re having an out-of-body experience for some days,” Amy said. “I couldn’t read to my kids. I couldn’t do anything normal. It wasn’t so

Making a Difference

much me but the fact that I was so worried I wasn’t going to be here to do it again in a year.

“So many people who have been through this process say to me, ‘This is the absolute worst it’s going to get. Regardless of your diagnosis, this is the worst,’ and they were right. Once you knew what you were fighting or what you had to do, it was so much easier. You knew you had a goal and you just had to keep moving. But, boy, those five days of not knowing were horrific.”

Diagnosis

On the fifth day Amy was home waiting for her friends — Jill Renner, Colleen Cornell and Lisa Hutcherson



Amy took advantage of a nutrition course offered at Wellness House in February. “Now I drink only soy — no more milk,” she said after taking the class.

— to arrive. They had planned to be there with her when the doctor called.

Amy was on the phone when they walked in the door and they could tell by the look on her face that the news was not good.

“I had just come in with coffee and it was supposed to be celebration coffee,” Lisa said. “We were sure it was going to be negative and everything was going to be fine, and it went the other way.”

The diagnosis was invasive triple negative ductile carcinoma.

Triple negative cancers do not behave the same way as other cancers, said Dr. Patricia Madej, medical director of the Hinsdale Hospital Breast Care Center who practices with Hinsdale Hematology Oncology. Most cancer cells express receptors for the hormones estrogen or progesterone or the protein HER2. Triple negative cancers have none of those indicators and may be more worrisome, she said.

The diagnosis certainly worried Brian — and continues to do so.

“The thing that scares me the most about this is that we have not met anyone else who has her type. You don’t hear a lot about it. It sounds good that you’re triple negative, but they can’t pinpoint

where it started. There’s no drug that has been developed for afterward. Most people are on chemo drugs for five years afterward.”

But before thoughts about what would come after chemo, Brian and Amy had to focus on the immediate need for surgery. Amy’s friends were there to help.

“We just went into action. We just sat around the island in the kitchen on stools and laid out the plan,” Lisa said of the group’s response to the diagnosis.

“We cried first and then we started making phone calls. We started calling people who we knew, people who had been diagnosed who used doctors they liked,” Colleen said.

“It was all about finding the best surgeon,” Lisa added. “It was quick research.”

Her friends also helped Amy set up a page on CaringBridge, a free online Web site that supports and connects loved ones during critical illnesses.

“That was all in the first two days,” Lisa said.

Amy and Brian ended up interviewing three surgeons before choosing one at Northwestern Memorial Hospital.

Once Amy and Brian knew what they were up against, it was time to break the news

to the rest of the family.

“I think Amy and I decided early that we weren’t going to shield the kids. But by the same token, sometimes they might be exposed to some things,” Brian said. “There’s no trial run. You can’t go back and rewind it and go, ‘Oh, we shouldn’t have done that. It didn’t work out.’ There’s no do-overs.”

The kids knew Amy wasn’t feeling well but they had no idea at first what was really going on.

“We got back from spring break and she went to the doctor because she said she had the stomach flu and then she told me and my brother she might have it,” Carly said.

Claire, who was 6 at the time, remembers hearing about her mom’s cancer at the playground. Her friend got things a little mixed up, and the story still makes Amy chuckle.

“I didn’t know my mom had cancer at the time,” Claire said. “I just thought that she was sick. And then (a friend) comes over and goes, ‘Your mom has breath cancer.’ And then I go, ‘Her breath is fine’ and then she goes, ‘I know but she has breath cancer,’ and I’m just like, ‘Cancer? What’s that?’ I didn’t know what kind of cancer it was. It’s scary when someone comes over to you and says someone has cancer.”

Amy’s mom, Jan Nuss, began coming up from Champaign to stay with the kids while Brian took Amy for tests or while they were interviewing surgeons. Her first reaction to hearing the news her only child had cancer was denial.

“I was rather shocked when it came to the point of, yeah, surgery is the answer, because I had had suspicious looking mammograms and they sent me for an ultrasound and the doctor just pooh-poohed and said, ‘Ah, there’s nothing there,’” she said. Two other times she had cancer scares that turned out to be nothing.

“So I just thought she’s not going to have cancer, but there’s a lot in our family, from my grandfather to both my parents, to the aunts — everybody — but no breast cancer, so where that came from is a mystery.”

Less than a month after she had felt the lump, Amy had scheduled her surgery for the following week at Northwestern.



Jill Renner (from left), Colleen Cornell and Lisa Hutcherson — Amy’s “three amigos” — helped out by walking the dog, taking her to appointments and dropping off meals in what Lisa described as an “orchestrated ballet.” “If any-

one ever asked me what’s the best town to live in, it’s Hinsdale, no doubt,” Brian Sr. said of the support they received. “If we would have been in the city we would have been lost.”



Amy enjoys a laugh with fellow Monroe School mom Beth Bernardi at the village's party in the park Aug. 14 at Burns Field.

"I am in a good place right now and ready to face what tomorrow brings," she wrote on CaringBridge the night before. "I felt anxious earlier today, but as tomorrow approaches, I am so ready to move forward. I have a strong feeling my peace comes from the prayers that have been sent my way from so many wonderful people."

Surgery

Amy had a complete mastectomy April 25. Spending that day in the hospital waiting room was one of the worst experiences for her husband.

"It was long and she got in late, so it was a long day,"

Brian said. "They were going to call me at the middle of surgery and tell me if it had spread. They just have no idea what they're going to find."

He finally got the call at 4 p.m., three hours after surgery began, and the news was good. The cancer had not moved into the lymph nodes.

"The surgery went as well as we could have hoped for at this point," Brian wrote on the CaringBridge site at almost 11 that night. "We have a long road to recovery but Amy is anxious to start her treatment. The last five weeks have been a roller coaster of emotions for everybody and I could not

be prouder of Amy. I am the luckiest man in the world to have met her some 21 years ago. Her strength and courage are to be admired."

As strong as she was, removal of the tumor didn't mean an end to Amy's fears.

"I really thought once the tumor was out of me the fear would subside, but I still have quite a bit of fear," she wrote on CaringBridge May 2.

She and Brian did have a chance to take a break and enjoy themselves before the first of eight rounds of chemotherapy on June 5.

"It was nice after the surgery that she got her strength back," Brian said. "We went out and did some fun stuff — went to some concerts and all of that."

"It's a strange disease. If you looked at her then, when she got diagnosed, and then looked at her four weeks after the surgery and you hadn't seen her, you wouldn't know anything happened."

Chemotherapy

Amy's first two treatments went fairly well. After the third, she experienced some troubling side effects.

Chemotherapy is designed to kill any undetected cancer cells that remain in the body.

"Chemotherapy goes to the cells that are actively dividing — and we're making the assumption or the inductive leap that cancer cells are actively dividing and those are the ones we want to kill," Madej said.

The problem is that other cells in the body, such as blood cells, also are dividing and become targets. People going through chemotherapy lose their hair because hair follicle cells are the most actively dividing cells in the body, Madej said.

Chemotherapy also can cause ulcers in the mouth, which Amy discovered after her third treatment. She also had a fever and ended up being hospitalized at Northwestern, where she was given antibiotics and a transfusion to help raise her red blood cell count.

As much as Brian tried to maintain a positive attitude, seeing Amy hospitalized was discouraging.

"I'm like, wow, this is really starting to go downhill," he said. "She couldn't eat or swallow. She had ulcers on her throat."

But he had to put on a good face for the kids. Although he was going to the hospital every day to be with Amy, he pretended to go to work so the kids wouldn't worry.

Grandma Jan was at the house to take care of the kids during every treatment and so Amy could rest afterward.

"It lasts about three days and then the second week you're up and moving, and I was like a tornado in the house," Amy said. "I would be cleaning nonstop and going shopping and all that other stuff."

During chemo Brian realized how fortunate they were to have brought home a puppy three days before Amy was diagnosed.

"Chief would take a nap with her every day," Brian recalled. The yellow lab also helped take their minds off things.

"No matter how she was feeling — and she was feeling pretty crappy a lot of days and so was I — he keeps you busy. He wants to go for a walk."

Keeping busy was a strategy Jan employed as well.

"You just want to trade places so badly," she said. "I've had my life. She's got little kids. It doesn't seem

fair, but I don't get to deal the cards.

"So to compensate for the frustration, I walked the dog. There were lots of things that I distracted myself with. I cleaned out drawers ... and washed windows. I just needed to be busy."

Seeing Amy feeling helpless on those days was the hardest thing for her mom to go through.

"I didn't want to see her suffer," Jan said. "She's been your shining star, the only one, so you don't want to see her hurt in any way."

Hair loss

Besides suffering from some dramatic physical effects of her chemotherapy, Amy had to face some emotional ones. Between her second and third treatments, she began losing her hair.

"When you first initially hear cancer, the first thing that runs through your mind is, 'I'm going to lose my hair.' I kid you not, and I think it's a woman thing," Amy said. "You don't mean to be all that vain but it's just the way it is."

"(Once) I got through losing my hair I think everything got a little bit easier. It was building up to that. It's



Amy's mom, Jan Nuss, spent most of last summer here watching Brian, Carly and Claire while Amy recovered from chemotherapy. She said she couldn't believe how many people helped the family out. "I think the thing that most impressed me was the support of this community," she said.

six weeks of knowing you will lose it.”

Amy’s friends were with her once again to support her. They went with her to pick out a wig and six accompanied her to Buke’s in Clarendon Hills to have her head shaved.

“We had wine and cheese and we went after hours and she shaved me and it was so surreal. You can’t really believe that this is really happening.”

Amy said she couldn’t look at herself in the mirror without her wig for months. Even at night she kept her head covered.

“I didn’t want my kids to see me,” she said. “If one of them got sick in the middle of the night or something, I didn’t want them to come in and there I am (bald).”

She used something called a halo made of synthetic hair that wraps around the head and can be worn with a baseball or cotton cap. She wore one to work out and also had one she wore to bed.

“I know that was very vain in itself, too,” she admitted.

But looking like herself was important to Amy.

“For me, if you look at yourself in a cap without any hair, you just look sick and I didn’t want to scare my kids.”

Amy’s hair had grown back in enough by April that she started going out without her wig. But she still felt self-conscious.

“I don’t want people to look at me and say, ‘Oh, that girl just got through chemo,’” she said about a week after she stopped wearing her wig.

Jan said Amy’s hair has been important to her since she was a little girl.

“I took her for a haircut once and got it too short and I thought I was going to have to glue the pieces back on her head,” she remembered with a laugh.

But Amy’s new short hairdo received good reviews.

“She looks good with her short hair,” Carly said. “But then she looks glamorous with her wig on.”

Her friends agree the short do is flattering.

“I have a feeling you’ll grow your hair out and then

you’ll end up cutting it,” Jill told Amy in April.

Wellness House

Just like her friends, Wellness House was there for Amy and her family when they needed it.

She attended On the Mend, an eight-week support group in September and October.

“I found myself not taking it home with me as much as some of the others in the group might have voiced,” she said. “I found myself kind of leaving it there, but when it was time to go back, I was very anxious to go back. Obviously I was getting something from it that I needed.”

The group helped Amy realize others had the same feelings and the same fears. It also confirmed her belief that she is generally a fairly upbeat person — more of a Tigger than an Eeyore.

“I think cancer just has a way of bringing it out of you more. I like to think of myself as more of a Tigger and keeping myself on the posi-

tive side.”

She also took advantage of the massages offered at Wellness House and the nutrition classes. And she knew she could always drop in on a support group if she needed to.

“It becomes a little bit of a silent battle afterwards because you don’t want to burden others with the talk, so that’s what the Wellness House is great for. You can actually go there and be with people in your same boat.”

Wellness House also helped the kids work through their mom’s illness. Amy remembered a story Claire told her about a boy at school whose mother had broken her arm.

“Claire said, ‘Well, I’ve got something worse to tell you.’ My mom has cancer. The boy said, ‘Oh my gosh, Claire, you’d better not go near your mom. You’re going to catch it.’ She said, ‘No, I won’t, because cancer’s not contagious.’

“I just have to say that was due to what she heard at Wellness House,” Amy said. “I don’t know if we had ever

used the word ‘contagious’ at our house after I was diagnosed. So had she heard that at school, she might very well have come home and maybe not said anything to me but stayed away from me, believing what her classmate had told her.”

Carly and Claire both participated in an eight-week support group for kids ages 6 to 12 led by Betsy Rubenstein.

“The first day I was a little nervous to hear about everyone, but then I got really comfortable around them,” Carly said. “We talked about the feelings other people have and we have. We got to write a letter to cancer saying how mean they were. I wrote that cancer sucked and I hated him. (Betsy) talked about how we all have the same feelings inside and we try not to let them show, I guess, not to disturb other people.”

The sisters didn’t always look forward to visiting Wellness House, as it forced them to think about something they often tried to forget.



Amy helps Claire get organized on the first day of school Monday at Monroe. Claire is in second grade this year; Carly (far left), who recently got her hair cut for Locks of Love, is in fifth.



Claire, 7, Brian Jr., 13, and Carly, 10, are happy to have their mom back after a tough summer of chemotherapy last year. One of Brian's responsibilities was walking their lab, Chief, who was just a puppy last year. "I felt more responsibility," he said. "It was hard."

"I wasn't always wanting to go," Carly said.

Neither was Claire.

"Because I knew everything about cancer then, because I already learned a lot from all those other weeks and so you'd be doing it over and over again," Claire said of the final sessions. "Actually those days I did actually learn more, so that's what I liked about it."

Brian Jr., who would have been the oldest kid in his sisters' support group and the youngest in the one for teens, met one-on-one with Rubenstein.

"It sure is comforting to know Wellness House is there," Amy wrote on CaringBridge last August. "It is so interesting, the WH is located right next to the baseball fields where for years I sat on the bleachers, not knowing that someday I would really need them."

Recovery

Amy went for her final chemotherapy treatment Sept. 11.

"It's time for me to put this chapter behind me," she wrote on CaringBridge three days after the treatment.

A few months later she realized that was easier said

than done.

In December, a close friend and cancer survivor went to the doctor because she thought she had a kidney stone. Instead, she was told cancer had spread throughout her body.

"She thought she was cured," Amy said. "After five years, you're considered cured. It never dawned on her that this was part of the problem, why she was feeling so lousy."

"So for me, I was so damned mad at cancer and I'm so sad for her and I was so terrified for myself at the same time."

Shortly after Amy learned about her friend, she had a checkup with her oncologist.

"I left feeling reassured because someone physically touched my nodes and someone listened to my lungs, but the fear doesn't go away," she said. "It's fleeting. It's not constant. I can have moments of sheer panic and then I can go, 'I'm going to be OK! I'm going to get through this.'"

"I know it's just this first year. I've heard it from everybody who's been through this — this year, especially three months after the treatment is over,

because you realize the drug is pretty much gone in your body and you're kind of on your own."

The holidays also made for some emotional moments.

"When I'm getting out the Christmas decorations and hanging up the ornaments, you try to stop yourself. You

really do. You really try not to cross that line. I don't tell anyone but I definitely have that fear — will I be here next year to do this?"

After the holidays Amy began seeing a therapist.

"I left and felt like a weight was lifted off me," she said. "Things are improving and I'm working on visualizing myself better. I think (of) that rather than visualizing myself sick and the fear of it all coming back. I actually felt a pain yesterday and I thought, 'Oh, no, that's from my workout.' I didn't immediately think, 'It's cancer.'"

Her therapist recommended she started keeping a journal and encouraged her to do all she can to take care of herself.

"I've never put myself first really," she said. "It's so hard."

By March Amy felt strong enough to see her oncologist on her own for the first time.

"It felt good," she said. "I said to him when he walked in, 'I'm a big girl now. I can do this all by myself.'"

He asked Amy how her hair was growing out and whether she was going to let it grow long.

"I was silent because I thought if my caretaker actually thinks I'll be here long enough to grow my hair out long — you know, it was kind of exciting for me to think he thinks I'll be here to see my hair grow."

Jan is confident her daughter will be around much longer than that.

"I'm sure with help from upstairs and everybody else, she's going to be fine," she said. "She's going to see those kids grow up, be a granny and go on girl road trips with her grandchildren."

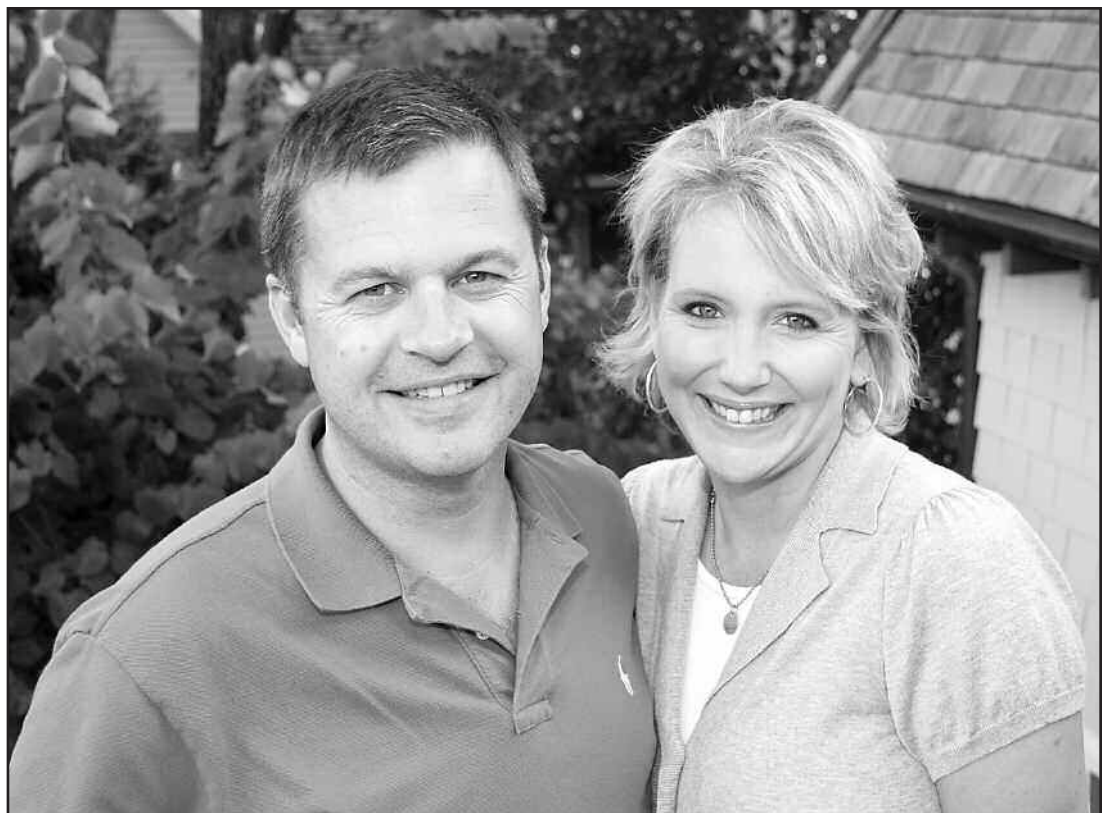
"I have no doubt that she's in very capable hands. They found it. They've taken care of what has to be taken care of and even if it comes back, it will be zapped again because she's determined."

For now, Amy and her family are taking every opportunity to have fun. After spending most of last summer watching Amy go through chemo, this summer has been sort of a make-good. And Brian and Amy have changed the way they look at life. The little things just don't matter any more, Brian said.

"It's like a really nice bottle of wine — the one you always say, 'Oh, no, it's not a good enough occasion to open it.' We don't think like that anymore," he said.

"We're going to live one day at a time and we're still planning for the future, but we open up all the old bottles of wine and enjoy them."

— *Making a Difference is a yearlong partnership between The Hinsdalean and Wellness House to increase awareness about the organization, which works to encourage, educate and emotionally support people working to overcome the effects of cancer.*



Brian and Amy started dating when he was 20 and she was 19. He said he would trade everything for her not to have had to go through this ordeal.