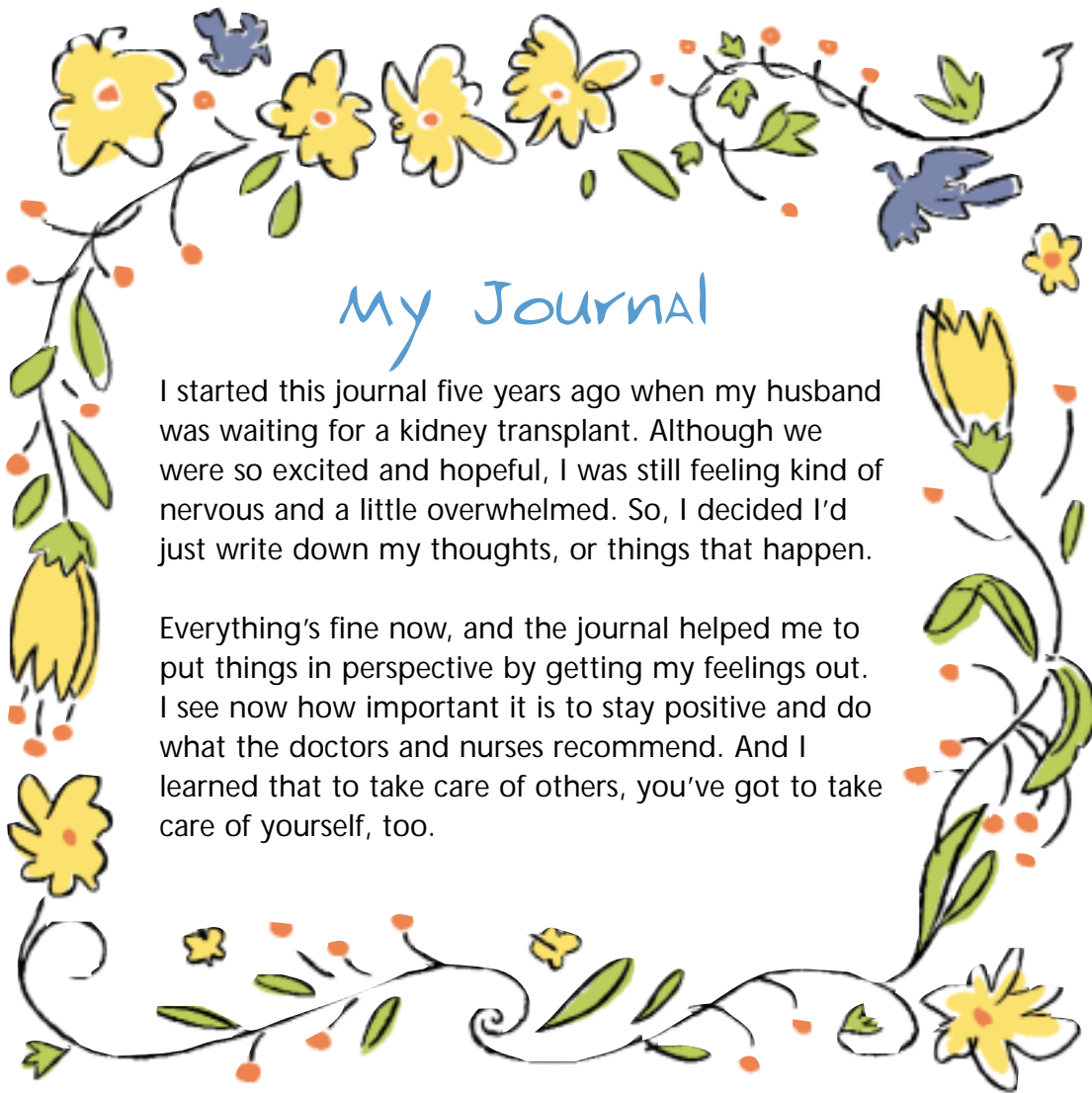


TAKING CARE of EVERYONE

The story of my husband's
kidney transplant



a caregiver's guide



My Journal

I started this journal five years ago when my husband was waiting for a kidney transplant. Although we were so excited and hopeful, I was still feeling kind of nervous and a little overwhelmed. So, I decided I'd just write down my thoughts, or things that happen.

Everything's fine now, and the journal helped me to put things in perspective by getting my feelings out. I see now how important it is to stay positive and do what the doctors and nurses recommend. And I learned that to take care of others, you've got to take care of yourself, too.

Waiting for a Kidney

My husband, John, has kidney disease. He's on dialysis now and we're waiting for a kidney. It's tough. Everybody always asks how John is doing, and that's only fair. He's the one who's really sick. But nobody — well nobody except my sister — has asked how I'm doing. And I'm just as stressed out as he is . . . maybe more. Because he's exhausted most of the time and I'm running around worrying and trying to take care of everything.

But I found an answer. If I can't find anyone else to talk to, then I talk to Chips the dog. Chips is a good listener. Probably because he knows he'll get a snack afterward.


Sometimes I wish that I were the one who was sick. Then again, I'm glad I'm not. I feel guilty for thinking that I'm glad it's not me.

It's not easy, but I know that
in the end it will be worth it.

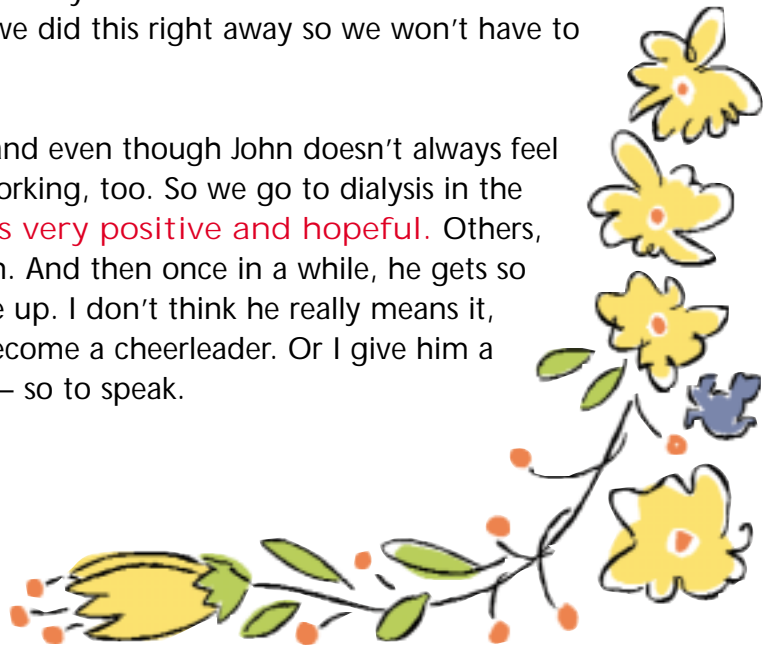


Ups and Downs

Sometimes people get a kidney that is donated by a family member who's in good health and whose blood and tissue are a close match. That isn't the case for us. So we're waiting for a kidney from someone who dies. The hospital explained that hoping for a transplant doesn't mean we're hoping for someone to die. It just means we're hoping that when there's a death, there will be a decision made to donate.

 The hospital also explained all the financial issues right in the beginning and helped us figure out how to make it all work. Knowing helps, but it may still be difficult sometimes to make ends meet. Still, I'm glad we did this right away so we won't have to worry about it later.

I'm still working full time and even though John doesn't always feel great, he wants to keep working, too. So we go to dialysis in the evenings. **Some days he's very positive and hopeful.** Others, he's just so tired and down. And then once in a while, he gets so frustrated he wants to give up. I don't think he really means it, but it's frightening. So I become a cheerleader. Or I give him a swift kick in the rear end — so to speak.



The Kids Want to Do “STuff”

The kids are scared and often argue with each other. I explain what John is going through, and tell them I worry too, but that we'll all get through this together and their dad will have a new kidney. It helps to tell them as much as possible. But the thing that they want most is to be able to “do stuff to help”, as they put it. I think it helps them feel more in control. So, I started to make a list of things that I think'll make them feel more involved:

- ✿ Start a scrapbook.
- * Go to the library and look up information on kidney transplant.
- ▲ Start an organ donor awareness program at school.
- ◆ Start a club with other kids whose parents have had a transplant or who are waiting for one like us.

I'll show them the list and maybe they'll come up with some other things. They'll probably ask what took me so long.

Doing WHAT I CAN

I've always felt very capable. So when John got sick, I tried to fix everything and make him well. But I finally realized that this is not something I can fix. This is something that just is the way it is. I think the only way someone can deal with this is to realize that it's out of your control. Otherwise, you'll go crazy.

John announced the other day that he wanted to make a will! I said, "Don't talk like that! Have you given up hope?" He assured me that even if he were going in for minor surgery, he'd want to make sure everything was in order for me and the kids. So we did it. I had a hard time dealing with this, but it gave him real peace of mind. And now we're both back to living with hope.

We talk about trips we've taken and the ones we'll take in the future.
We always try to keep a positive outlook.

*Recovery was not to be seen as a smooth slope, but as a series of radical steps,
each inconceivable, impossible, from the step below.*

-oliver Sacks

My Life Is Different

I've had to take on responsibility for things I didn't used to do. Like paying the bills, and taking care of the car, and mowing the lawn.

I started to feel overwhelmed by it all until I gave myself permission to let some things go. Because some things just aren't as important anymore.

I decided the house doesn't have to be as clean. And if I don't make the bed in the morning every day I don't agonize over it. Also, I don't iron anymore at all — we just wear T-shirts and jeans. And I don't fix dinners that take a lot of time. In fact, if the kids are over eating with friends, and John is out, I'll just heat up a healthy frozen dinner for myself. It helps me to remember that all this is just temporary and that things will eventually get back to normal. Although if I never iron again, it'll be OK too.

Helping John By Helping ME

John's condition has really taken over our lives. **But I realized I needed to do some things on my own . . . to have my own life, too.** So I took up jogging. Well, maybe not exactly

jogging. More like energetic walking.

But it's great — a terrific stress outlet.

And I've also taken up ceramics.

This happened because one evening I happened to "jog" past a little place that sells stuff you paint. And they're open evenings, when John goes to dialysis.

It's FUN!

It recharges me just to get away from everything and get something fresh and new into my life.



And I think I'm better at caring for John because of it.

When the Phone Rings, WE think- Is this It?

Anytime the phone rings, we wonder if this is it. Especially if it's in the middle of the night — which always turns out to be a wrong number, like somebody trying to order pizza! We try not to think about the phone all the time. We try to just wait for the call to come in its own time.

Sometimes it seems like we're on a string. We're afraid to go anywhere for fear they'll call and we won't get back in time.

Before, we used to take little trips, just the two of us. But after John started dialysis, we stopped.

Then last month we decided [we have to live life now.](#) John's brother had invited us to visit and we said yes. We had our dialysis center make arrangements for dialysis near his house. And it was a great trip. We both felt excited just going someplace. And the transplant facilities took our number so they could reach us if a kidney became available.

Talking About it HELPS

The transplant center has been very good about giving us advice and information. And they explained how we could get more information online through a computer at home or at the library. They also told us about a support group we could go to. Some of the other people in the group are waiting for a transplant, and some have already had the operation. It's nice to talk to others who've gone through this. You don't feel so alone anymore. Some of them have even had a second transplant because the first one didn't take. John and I are glad we went and were encouraged by everyone there.



The Kidney Is Here!

We got the call early one evening. We were both nervous because even though you get the call, you may not get the kidney. The hospital always calls in several people to do what they call tissue typing and cross matching with the kidney they have. We were lucky — the kidney was a good match with John. The operation was long but it went fine and John is in ICU now, sitting up in bed.



He feels terrific already.

He wants to go to
That Steak Joint and
PIG OUT.



I'm thrilled.

But I'm so tired I could fall asleep just leaning on this wall.

Spending Time in the Hospital

Sometimes John wants me to spend the night at the hospital. It's not always necessary but he wants me to. And the hospital recognizes that this is important to the patient. So now I keep a bag packed in the car with certain things:

Don't Forget

1. a clean pair of comfy sweats
2. a warm sweater
3. woolly socks
4. my bunny slippers
5. granola bars, baggie of crackers, other snacks
6. tea bags, iced tea mix
7. magazines and books
8. My Journal

If I decide to stay, then my mom will come and pick up the kids after visiting hours. Even if I don't stay over, the comfy shoes and sweater come in handy. And the food tides me over until I can get a meal. I also carry around this journal to write things down, plus some magazines and a couple of books for when John naps. I hate for people to see what books I'm reading because they're these old romance novels I found in the hospital library. But they keep my mind off everything else and I try to hide the book covers behind this journal.

The first wealth is health. -Emerson

The Hospital Routine

John dozes on and off all day and ends up getting a lot of sleep. On the other hand, I'm a mess. Hospitals get up very, very early, so I'm not getting anything like normal sleep. The nurses come in about 5:30 AM to update the charts — which wakes me up even though they don't mean to. And the doctors usually come in around the same time. Even if I don't stay over, I like to be there then with John because four ears listening to the doctor are better than two. Then later, if I'm spending the day at the hospital, I try to follow John's example and catch a few winks whenever I can.

I've also learned to get up and stretch around and get a little exercise now and then. I walk around the halls and on the grounds outside. The fresh air always clears my head and makes me feel better. And I started taking the stairs to the cafeteria — sometimes just to buy a banana. It's a great snack if I wake up hungry here in the middle of the night and I can't go padding into our kitchen for something to eat.

“Is there
ANYTHING
I can do to help?”

John’s recovering fine from the operation, and the doctor says he can go home tomorrow. Five people called the hospital today and asked if they

could do anything to help — which is nice. I used to say “Oh thanks, everything’s fine.” Now I realize I’m practically killing myself trying to do everything. **I’ve ALWAYS had a hard time asking other people for help. Or accepting it. But now I need to start doing both.** So today I started giving them ideas.

I told Janet maybe she could drop off a casserole for me and the kids. And I told Marie it’d be great if she could make something for dinner the next night. And when Sheila and Bill called, I said: “Yeah, could you maybe mow our lawn?” (I didn’t tell them it looked like a jungle.) And they all said no problem — they actually welcomed having something to do!

I also asked another friend if she and her husband could call other people who want to know how John is doing. Sometimes when I get home, I find all these messages on the answering machine and I’m just too tired to talk.

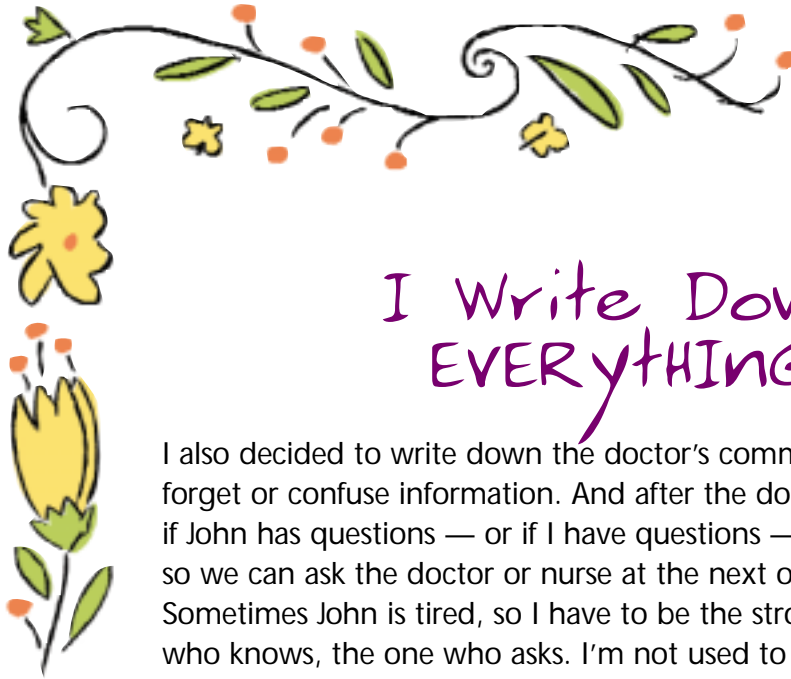
Since I have a spare moment and John is napping, I decided to write down a list of things I’d like people to do — so when they ask that question, I can look over the list and give them a suggestion or two. Not everybody wants to cook meals. And to be perfectly honest, there’s one neighbor whose meat loaf is so bland I’d rather eat cardboard.



MY Wish List

1. Bring food to the house.
2. Pick up the kids after school.
3. Take the kids to their activities.
4. Call others and let them know how John is doing.
5. Mow our lawn.
6. Send John a card.
7. Send me a card.
8. Check on John when I have to work late.





I Write Down EVERYTHING

I also decided to write down the doctor's comments so I wouldn't forget or confuse information. And after the doctor's visits, if John has questions — or if I have questions — I write them down so we can ask the doctor or nurse at the next opportunity. Sometimes John is tired, so I have to be the strong one, the one who knows, the one who asks. I'm not used to being this way. So it helps me to have the information written down. Getting answers is very important. Otherwise, we worry. And usually for no good reason. But when we have the facts, both of us feel better.

A sound mind in a sound body is a short but full description of a happy state in this world.

- John Locke



Back Home

John is back at home now recuperating. I took some time off when he was in the hospital, but I'm back at work again now. I feel torn between my job and taking care of John. I feel guilty every morning when I go out the door. On the other hand, he's probably relieved to see me leave — since he must feel I'm a bit of a nag about making sure he takes his medications.

So we talked about it, and John said not to worry. He said he wanted me to get back to my normal life. We agreed that we would both do what we could, and that John would do more and more as he started to feel better. He also said it was his responsibility to take his meds, so I shouldn't feel like I have to take on everything myself.

Pills, Pills and MORE Pills

He has to take A LOT of pills every day — at certain times of the day — and he'll have to take them for the rest of his life. I remind him that any day on pills is better than a day on dialysis. **And it's important to take every single one.**

To make it easier, we sort them all out at the beginning of the week. We use one large sandwich bag for each day of the week, and then we group the pills inside smaller bags that go inside the large sandwich bag. Each of the smaller bags is labeled with the time of day he is supposed to take those pills. This way, John picks up one sandwich bag each day and he's all set.

The medications are very expensive, so I'm glad the hospital helped us figure out how to pay for them. I can see how some people might be tempted to stop — especially as they start feeling better. But John knows that if he stops taking them, his body will reject the kidney. And that would mean he went through all this for nothing.

The doctor told us the pills can have some side effects, and that they can sometimes cause people to have trouble having sex. He said that this can happen even though most people feel a lot better after a transplant and are more interested in sex than before. And that this can happen to men and women patients, although for different reasons. In John's case, the doctor said if we had a problem, we should be open about it with the transplant team, because solving the problem could be as simple as changing John's blood pressure medicine.

Just Say No... to Candy Bars

John feels stronger every day and he looks good, although his face is getting sort of round and he's starting to put on weight. Puffiness, they say, is a side effect of the medications. Hunger is another — because the medications also increase your appetite. Besides that, John is so happy not to be on the restricted diet he had during dialysis that now he wants to eat everything! Since he's home during the day, I put things like apples and grapes and little baggies of cut-up carrot sticks and celery on the top shelf where he'll see them right away. And I really watch what we have for dinner now and what we keep on hand for snacks. John knows he'll have to watch his weight more carefully now.

Couch POTatoes NO MORE

Something great has happened. Instead of coming home and sitting on the couch, John and I are exercising together. I feel so much closer to him than when we just would sit there and stare at the TV. I taught John how to "energetically walk," and now we go all around town with Chips running behind us. We talked to the doctor and he said that exercise was a great thing for the health of John's new kidney. John took our old bikes down from the attic and is fixing them up so we can ride when the weather gets warmer. And the kids are even working on a way to hook up a wagon to their bikes so that Chips can come along, too.



Coping with Dr. Jekyll AND MR. HYDE



John has always been so even-tempered. But now if he's having a bad day, he's REALLY out-of-sorts and demanding.

I know he's tired of being sick.

I understand that.

But I still feel hurt.

They say the people who are the closest get it the most. Sooooo I just take a deep breath and silently count to 10. If that doesn't work, then I just say I need to get a cup of coffee and I'll be back in 20 minutes. Usually, we're both better when I return.

I wasn't prepared for the mood swings.



As a result of the steroids he has to take after the operation, John is incredibly happy one minute — singing along with the TV commercials — and the next minute, he's crying in his cereal. The doctor said this happens to lots of patients and it will pass, and not to take it personally. Knowing this helped. And it did pass. And later, when John was back to being himself, he joked that cereal always makes him cry.

patience is the art of hoping.
- Vaouenargues

Oh No, NOT AGAIN

John was home for a while and doing really well and then he had a rejection episode. ***The doctors tell you that, even if a patient is doing well, this can happen, but it doesn't usually mean you'll lose the kidney.*** It's still hard to deal with.

Because you start wondering if this is the way it's going to be, if he's going to be going back in the hospital all the time. But the doctors say it's not like that. They say that the most important things you can do are to stay healthy, stay in close touch with the transplant team and do your monthly lab tests to catch rejection early.

So I have to remind myself it's only temporary. And to stay positive like I did before, through all the ups and downs.

Bad days and bad times are not permanent.

Happy Birthday

Every year we celebrate the anniversary of the kidney. And each year after the party I open up my journal and write a new entry. We have a special family dinner with the biggest steaks we can find. Even Chips gets to celebrate.

And this last year, John and I took a little second honeymoon too. While John didn't carry me over the threshold this time, he says that if it weren't for the operation, he would have!

We have a greater appreciation of life now, and we don't take anything for granted.



*We are so grateful
for everything!*

Don't Forget to Ask-

John and I still go to the support group — but now we go to support others who are waiting for transplants. And we tell everyone the same thing:

Ask Questions.

The more you know, the better you'll feel about what's going on.

Ask For Help.

People really want to help you. Let them.
They'll like doing it, and it'll make life easier for you too.



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Provided as an educational service by:

Roche Laboratories

A Member of the Roche Group

Roche Laboratories Inc.
340 Kingsland Street
Nutley, New Jersey 07110-1199

Plandex 104122
Lot 0000122104
18-002-104-034-057