

What Your Doctor Won't Tell You About PKD*

*But You Need to Know

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Smashwords Edition

~ For Jenn ~

Disclaimer

The advice in this book is the opinion of the author. The author is not a licensed physician. He merely played one with a girl at daycare when he was six—it was her idea, by the way (at least that was my story and I see no reason to change it now). He holds no advanced degrees in medicine or anything else. He intends purchasing a PhD from an online diploma mill, but has yet to get around to it. His sole qualification to write about PKD/PLD is having experienced it, which in this culture is no qualification whatsoever. Nothing in this book should be interpreted as medical advice or advice to forego, refuse or ignore the medical advice of a licensed physician or specialist—bla bla bla.

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Foreword

This may or may not be a book for you. If you are looking for help picking a doctor, or information on the latest treatments, research papers, experimental results and new treatments for Polycystic Kidney Disease (PKD), I'll refer to you [a great book on that side of things](#).

This isn't that kind of book. This is more of a travel guide by an experienced traveler, with notes on what to do and not do, what to eat and what sights not to miss. Just think of Polycystic Kidney Disease as your Route 66

and you'll get the idea. All roads have potholes and PKD is no different. So, if you're buckled up, let's see how many of them we can help you miss.

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Introduction

PKD: Three letters that monkey wrench your life...

When did you find out you had it?

Remember the day?

Of course you do. You'll never forget it.

I learned I had PKD and PLD when I was sent by a nephrologist for a sonogram of my liver. The technician was a nice gal who thought I already knew what I had and how bad it was, so she was nice enough to turn her screen so I could watch as she scanned. (Ooops!)

Me: "Can I look?"

Her: "Sure."

Me: (Watching some big black ovals go by like tar pits on google maps) "What are those black spots?"

Her: (Matter of factly) "Those are the cysts."

Me: (A ton of stone settling onto my chest...) "Are there... a lot of them?"

Her: (Thinking about her boy friend) "Oh yeah, you've got dozens of them."

Me: (A sense of peace and doom settling over me, but calm) "How big are they?"

Her: "They're big. See this one here? It's about the size of a goose egg. There are a lot of those."

Me: (Huh? What?) "Are they all over the liver?"

Her: "Uh huh, they're everywhere."

Me: (Too numb to think, but calm, very calm) "Aaaaah."

Great dialog, huh?

Well, it was a refreshing to be told the truth, shown the truth like that. But it was a life changing moment, too. Right then I learned I was mortal and not, as I suspected, a superhero with amnesia, but just another soul with a very short pass on the greatest of all rides—life.

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Coming to terms with PKD

They say there are five stages to grief and loss: denial, anger, bargaining, despair, and finally, acceptance.

I went through them all. You will too.

Denial?

Upon feeling my first bulge (and knowing my dad had PKD), I was convinced I had appendicitis and called to try and setup a laparoscopic appendectomy. Yeah, I know it was dumb. If that's not denial, what is?

When I discovered that, oops, you have to be a doctor to do that, I went to the ER. Told you I was dumb. Three hours, X-rays and \$3000 later I went to see a nephrologist and was referred to a sonogram. With that, denial was over.

Never been big on anger, and who do you blame, anyway, for PKD? Your parents? Your genes?

I went right into bargaining. I bought and read books on treatments. I went to see arthroscopic surgeons about deroofing (opening and draining) cysts. I contacted the Mayo for liver resection (removing). Notice how everything has a special name in medicine to make it all sound complicated? Hmm... wonder why?

Anyway, I bought health insurance that would pay for surgery. I looked into renting a house while at Mayo. We talked about taking the dawg and who would watch the cats. I was ready to go. The plan was to have a laparoscopic liver resection but then I had a CAT scan and got to enjoy drinking a lot of grape flavored white goop. It's revolting but putting it in the freezer helps a lot. Then, when I got to the CAT room they made me drink some more luke warm, which is the perfect example of how much they know or care about making things pleasant for patients. When I learned my kidneys were the main problem that was enough for me.

I'm not sure when I realized that the whole doctor thing wasn't for me, but somehow I got there. I'm very

glad I did. For me, it's the right answer.

As for despair, well, I took a few walks in the woods by myself. Next thing I knew I seemed to get it, to really understand that I was just passing through, that all I had, all I really had, was today.

So that was my trip through the five steps. It wasn't easy, but I made it. You will too.

You may have been twenty when diagnosed, or, like me, you may have been closer to fifty. Whatever age you were and whatever happens... regardless of whether you end up getting one or more transplants or not, there are things you need to know and your doctors, no matter how nice, competent or helpful, can't tell you—because they don't know. Not really.

Only those of us who have lived with a belly full of cysts know what it's like.

Like anything else, there are some tricks to the trade, ways to live with it, because it isn't going away. Live right, use your head and you can minimize the effects and maximize your enjoyment of the time remaining to you.

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The Facts

There is no cure.

Doctors have tried everything over the years worldwide:

Syringing out cyst liquid—doesn't work—it introduces infection into the kidneys.

Opening cysts—no dice—they close and fill again.

Deroofing cysts (taking the top off)—it works, sort of—they grow back in other places, like a bush trimmed back, pushes out dormant buds.

And, of course, the silver bullet, kidney transplant.

It works—for a while—if successful—though nearly a quarter of them fail right away. If it takes, you can get up to ten or twelve years out of one before it needs replacement. Yup, that's right. They don't last forever. You may need a second or third. Ready to sign up?

Not so fast. There's a 5 year wait after you join the 100,000 people on the [UNOS list](#).

And you better have good insurance, because they're not cheap: [quarter million plus](#). That's why so many travel to China, India or Thailand to buy one—well, that's what they're doing—relatively cheaply. A lot of poor people sell one to try to stay afloat and some, [including Chinese political prisoners](#), may not have a choice in the matter. It's a wonderful world.

One out of 500 have adults have PKD.

That's a lot of folks—about fifty million worldwide. So you're not alone. Feel better? Na, me neither.

Only about half of PKD people will progress to kidney failure.

So only about half of those with PKD will ever be eligible for kidney transplant. Your kidney may be the size of a football, but if it still works at all you're out. How many of those with kidney failure can qualify for a place on the list is problematic—too old, too fat, too poor, too unhealthy, can't wait and spend years on dialysis? Tough break, kid. The point is that transplantation is not an option for most of us. So, regardless of whether transplantation is the answer for some, for most of us it's not. For most of us, it's just something we live with.

[PKD is terminal. It will kill you.](#)

[How?](#)

[Heart disease will take 35%](#)

[Infections will take 25%.](#)

Aneurysm will take 6%

Intracranial hemorrhage will take 5%.

Stroke will take 1%.

And kidney failure will take the rest.

The average age of death for adults with PKD is 60 years.

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What to expect?

Enlarged Belly

As you probably already know, your waistline is going to expand. We're not talking about a little "pinch an inch" flab here. We're talking about a big belly. People will think you've got a beer gut, are pregnant or fat. And you don't get the fun of drinking the beer, overeating or making a baby.

My mother thought my dad was fat and had him on diets. They didn't work. Even on the most stringent diet it's hard to lose your liver and kidneys.

If you've really hit the jackpot and have PLD too, your liver will grow cysts as well and, as it does you get a pain in your shoulder. Yeah, I know, weird, but it's true. [Something to do with the connective tissue stretching](#). Also, you'll feel your liver rub on your ribs—ribs are sharp! I have new sympathy for women in certain gonzo video productions faking amorous delight while perched on the edge of tables and countertops. Their behinds must feel like my liver. At least my ribs aren't cold and I don't have to pretend to enjoy it, so I guess I've got it easy.

So you're going to look fat and that's not easy for some of us, vain creatures that we are. It may take some adjustment on your part. You may need to give up mirrors, because they won't show who you are, but only what other people see. And you may even start looking beneath the gauche exteriors of those you run into at Walmart. After all, they may be just as unique and fascinating as you are inside.

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Endurance

PKD will affect your ability to be physically active. Many people with PKD still run, dance, play sports and pursue active lives, but everyone is affected to a greater or lesser degree by the added weight and bulk of cysts and loss of lung capacity.

That's one kind of endurance, but there is another more important kind, the kind that allows men and women to persevere and overcome difficulties when mere logic would suggest they might not. That endurance PKD cannot take from you.

PKD is a disease of the body, not the soul. You are NOT your gut puppet. Regardless of the dogma of the learned acolytes of atheism, you are more than chemicals, atoms and electricity. You are a soul, a spirit, a mind, a force, a will. You have the power to transcend your body's physical limitations. You can...

...force your heart and nerve and sinew

To serve your turn long after they are gone,

And so hold on when there is nothing in you

Except the Will which says to them: 'Hold on!'

Kipling knew. Read the whole poem: "If" [here](#).

And there is another poem written by another man who knew hardship and endured.

Invictus (*unconquered*)

Out of the night that covers me,

Black as the Pit from pole to pole,

I thank whatever gods may be

For my unconquerable soul.

In the fell clutch of circumstance

I have not winced nor cried aloud.

Under the bludgeonings of chance

My head is bloody, but unbowed.

Beyond this place of wrath and tears

Looms but the Horror of the shade,

And yet the menace of the years
Finds, and shall find, me unafraid.
It matters not how strait the gate,
How charged with punishments the scroll.

I am the master of my fate:

I am the captain of my soul.

The man was [William Ernest Henley](#). His life was not easy, yet he endured. Can we aspire to do less?
PKD can only affect your spirit if you let it.

Don't let it.

I know a young woman in her twenties who has PKD. Her swollen kidneys won't allow her to work, dance or even walk. She has seizures several times a day every day. Yet she refuses to be cowed. Jenn is her name. What a spirit, what a soul this woman has. She counsels newly diagnosed PKD sufferers on dailystrength.org and her spirit shines through every encouraging word she writes.

She's not the only one. There are many courageous people out there. Hardship, pain, tragedy all change people, many for the better. Many rise above the challenges to become more than they might have been without it.

Be one of them.

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Clothing

Forget fashion.

Tight clothing is not a good match for PKD. Comfortable clothing is stylish PKD wear this year—and every year. You deserve to be comfortable and so your clothing must be nonbinding. Pressure on cysts hurts and restricts your movement.

I had to give up Levis worn with a belt, but I found a suspender held jeans worn by loggers here in Oregon called [Prison Blues](#). They're great for working and they don't squeeze my cysts.

And, suspenders... they're perfect for me. Elastic slacks, sweat pants and active wear pants are another way to go. Russell Athletic makes some great [stretch pants](#) and sweats in 100% cotton. They're affordable and stretchy without feeling slimy like polyester.

Make mine a tee shirt with a long tail, pocket and generous cut. I get em [here](#). Oh, and [cotton is the only way to go](#). It's softer, more absorbent and, in double knit, stretchy to ease stress on cysts. It may be called “the death fabric” by mountain climbing rescue teams in Yosemite, but we won't be tackling Half Dome any time soon, so we should be safe.

Flaunt convention. Dare to be comfortable.

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Bending

Bending over to pick something up won't stay easy. As your waistline grows it's going to get harder. Imagine duct taping an inflatable pillow filled with water to your stomach—or, since we're imagining—inside your stomach cavity. Remember how you feel after Thanksgiving dinner? Well, you'll feel that way, more or less, all the time.

If you wear loose fitting clothes and take it easy you'll still be able to pick stuff up but try to do it as little as you can get away with. What happens is that your muscles squeeze the cysts and if a cyst bursts or bleeds it can put you in bed for a few days with what doctors so inadequately call “flank pain.” The term “flank pain” describes the feeling about like the term “mild discomfort” describes giving birth.

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Pain

What causes it?

It can be several things. [Infection](#) can cause it. Bleeding can, too. Rupturing a cyst can. Aneurysms in the brain can. But so can your muscles and the more muscular you are the worse it can be. Serving during tennis, throwing a ball or anything else, any vigorous contraction of the back muscles can compress cysts. Even walking can hurt.

We're wired to react to pain by tensing our muscles, but tensing up can make the pain worse. With practice you can learn to relax your back muscles and ease the compression and resultant pain from your cysts. Stretching, deep breathing, moving slowly can all help. Pay attention to your body and the messages it is sending you and you will learn how best to minimize the pain.

How bad can the pain be? Some of the more poetic among us liken the pain from compressed, bleeding or infected cysts to a red hot stiletto driven into a kidney. It can be bad enough to need a pain pill to take the edge off. Learn to move gently and stay on your back in bed and it will get better in a few days. For once when they say "bed rest," they're right.

Flank pain can stay with you for days, weeks or months. As PKD develops, it becomes a part of your life, a part of your day. It creeps in and soon it's always there. Morning "stiffness" or "flank pain" becomes morning and evening pain, and, eventually it's just there all the time. When compared to the real pain people have to survive in accidents and war it puts it into perspective as the inconvenience it is.

Pain is no fun, obviously, but you know something? I'll be accused of masochism for saying this, but I just went through a couple days of it and, when it lessened I was kind of sorry to see it go. Not that I enjoy it, but I do enjoy mastering it, dealing with it, handling it and still keeping on. I enjoy knowing that, despite the pain, I can still do what I need to do. I don't talk about it a lot. I just deal with it.

Pain is one of the things we have in common with all living things, everyone who has ever lived has felt it. Most of them had no choice. I can choose to take a pain pill if it gets to where I can't move, so for me it's like walking a wire with a net---one they didn't have. The idea that we should never feel pain is a modern one, one that says much about how we live. I don't think it speaks well for us—as individuals or as a race.

Pain is now a part of your life. Learn to deal with it, get along with it, tolerate it, avoid it when you can. You'll persevere.

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Stretching and Exercise

You need them, of course. Your body cries out for them every day, or it should. But exercise for the PKD crowd requires finesse. We can't do all the things we used to do—at least not without paying a price.

There are two problems to look out for. The first is compression. When you do something requiring strength, you flex the muscles of your stomach and torso. This compresses your cysts and may rupture or cause bleeding in a cyst or kidney that may put you in bed with pain bad enough to keep you there.

The second thing to look out for is sudden movement. Jogging or jarring cysts can result in the same pain as compressing them. When walking or hiking you'll need to be careful not to trip or fall or even slip by stepping on a rolling stick. You know the feeling of stepping down onto a step that isn't there? Don't do that. Seriously, try not to.

Of course, everyone is different. You'll learn what you can and can't do by trial and error. For me, the worst mistake I can make is to try to pull something from the ground in a bent double posture. Have I learned yet? No. I still do it.

The funny thing is you'll know when you've torn or ruptured a cyst even though it may not hurt right away. You'll get to know the feeling. It hits you the next morning, when enough bleeding has built up pressure in the kidney. No fun.

The stronger you are, the more active you've always been, the more you'll try to do, and the more you'll damage your cysts doing it. If you're a guy who's used to doing hard labor or exercise, you're going to need to learn the hard way. So push your limits, pay attention, and learn what you can and can't do. Sure, you'll overdo it. So what? It won't kill you. Lift that stump, pound down the court, make that extra effort to send that ball just

that much farther. Then spend a couple days in bed with that book you haven't had time to read, and next time (or the time after that if you're a slow learner like I am) you'll be a bit more careful.

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Nausea

You can expect to have some nausea. Not puke your guts out nausea, I hope, but more like just getting off the teacup ride at the fair nausea. It gets worse when you exercise vigorously, overeat or otherwise stress your cysts.

What causes it? It may be the pressure the cysts place on the stomach and intestines as some theorize, or, as is my theory, it's just the cysts' way of defending themselves by letting you know it's time to back off.

The nausea, like the pain, is something you can resist and learn to live with.

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Community

If you feel the need for comparing notes and exchanging sympathy with other PKD folks, there are plenty of forums to choose from. Here is [one of the best](#).

When you're new to the PKD game and need pointers from those who have been there, it's a real asset. You can ask questions and share your situation if you like. Many of the people there are amazingly knowledgeable and in fact, know more than many doctors about what it's like to suffer from PKD. And most if not all are compassionate and empathetic. It's a good way to learn about others' experiences, too.

Note from PKD man: I choose not to participate in these forums because PKD is not my whole life. It's just a thing I have to live with. It's not my major interest. In fact, I find it a bore to talk about, or for that matter listen to others talk about their health problems. Just my opinion.

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Working

You can expect to have less energy, get tired sooner and easier and have less stamina. If you must work then you must work. You do what you must. If you must do physical labor it's going to be tough. There will be good days and bad days, but the trend will make itself clear.

I run into a wall about 3 in the afternoon and the best way to deal with it is to either take a nap or relax for a while. If you have to work full time then you probably can't do that, unless you have an understanding boss. I happen to have just that as I am he—my boss, that is. If you have a boss, you might want to tell him that [a nap increases productivity](#). It may not convince him, but it's worth a try.

The important thing is to see this “laziness” for what it is—the stress PKD puts on your body. Don't beat yourself up over it. PKD's doing that already.

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Sitting

[Sitting is bad for you.](#)

That we know, and have known for years. For everybody, not just for those with PKD. Yet we keep doing it. Social convention requires it.

The way you have to sit to be comfortable may change as your cysts grow. Find what's comfortable for you and don't force yourself to sit in a posture that cramps your cysts. Again, just listen to your body.

How will you know how to sit? You'll know, believe me. Cysts don't suffer in silence. If you need to reduce your time on your ass or give it up completely, then do it. Charlton Heston wrote his memoir standing. You can use a computer while standing or even dictate to a wireless mike if you want with the right software. There are also [kneeling chairs](#) you can try.

Think creatively. Eat standing up like you're at a chic Paris food bar. Why not? If it works, do it.

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Sleep

Sleeping is not going to be like it used to be.

To begin with, depending on whether your cysts are actively growing, and whether you have cysts in your liver or not, it may be hard to sleep on your back, left or right side. As for sleeping on your stomach, those days are over—probably.

The bright side is that this too, shall pass. It changes from day to day and it will get easier. And, you guessed it, it'll get harder, too. Damn!

I find it helps to have a [body pillow](#), or just a pillow for your stomach. I'm not sure why it works, whether it's the support or just the comfort, but work it does. It can be a regular pillow size but make sure it's stuffed with cotton, feathers or [buckwheat hulls](#), not slimy fiberfill, and the same goes for your regular pillow.

And another thing: you may notice you sleep warmer than you used to. It may be because of a low grade infection or maybe just because your organs are crowded. But it's something I've noticed it seems to be a change that's here to stay.

You may also need more hours of sleep than you've been used to. The important thing here is to be flexible and listen to your body. If you're tired, and can sleep in, do it. It can really help to reduce pain and increase your energy level.

And sleeping brings us to...

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Urination

Space in your abdominal cavity, like land in Malibu, is at a premium. And it will become more so every day. With all these bags of water in your belly there isn't going to be much room left for a full bladder. You may not notice much difference during the day, but you will at night. On bad nights it will seem as if you spend more time urinating than sleeping, but hey, that means your kidneys are working, right? And that's a good thing.

You might want to cut your intake of both food and liquid for several hours before bedtime. I find it's better if I stop eating 4-6 hours before bed. Another benefit of eating earlier is that with less in your intestines there is more room for urine.

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Constipation

It's not an option. The average jerk on the street can walk around compacted most his life eating trash food, take a laxative once in a while and, other than a bad breath, lethargy and maybe a touch of colon cancer, be fine. He's got the room for it, you don't. As a look at your latest CT will tell you, you've got an inch or two between your swollen kidneys and your peritoneal lining. There's no space to waste. You've got to keep your intestines moving. Like we sci-fi fans say, "The roads must roll!" Thanks Dr. Heinlein.

So, how do you morph from a normal American with colon impacted with sugar, white flour and fat, into a pooper hero? Kick the styrafoam bread habit and go with sprouted whole grains. Eschew the corporate caramel colored white flour imitation whole grain crap most stores carry. Read the label and make sure it's the real thing. This isn't penance. Find a bread you like. Slathered with real butter and real honey it's great. Better yet, find a local bakery and get it fresh. Fresh bread, by the way, is baked today. No self-respecting Roman beggar would have eaten the rubber bread we eat. Ah, progress.

And don't forget the fresh fruit, fresh vegetables. Eat what you like.

Do you have to give up hour old crusty sourdough? Na. Just remember it's a treat, not a staple. Your guts need grist for the mill, something peristalsis can push against, something indigestible, like grain, uncooked vegetables, fruit with skin, seeds, stuff like that. Eat like a monkey. They're a lot smarter about eating than we

are. And you see less of them in ER's.

What if it's too late?

Okay, you screwed up and got a little carried away and now you've got the intestinal equivalent of writer's block? Get some whole [psyllium seed](#). Forget the brand names that mix four parts sugar and flavor to one part ground seed. Get the seed in the bulk department of a good store and take a spoonful in your mouth and wash it down with a glass of cold water. No taste. Like swallowing sesame seeds whole. Done. Psyllium is amazing. It swells to provide bulk, is indigestible and forms its own slick viscous lubrication.

And another thing. Your body needs to be trained to evacuate at a certain time of day. After the morning's coffee or tea is as good a time as any. Just before a shower is another. Our bodies are creatures of habit. Remember Pavlov? Train your colon as well as he trained his dogs and it will all come out all right.

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Breathing

You've always had great breathing, right?

You were way too smart to smoke, right? Thought you'd always have good lungs didn't you?

Well you do. You just won't have room for them to fully expand. There won't be room in your rib cage for your kidneys, liver and your expanded lungs, too, so, if you picture the alphabet as a graph of lung expansion with A being your lungs empty and Z being your lungs expanded with air, your new breathing will begin to shrink. You may begin to notice when a big breath gets you from A to M. On a bad day when, for whatever reason, you've got some swelling going on, your breathing may range from A to H.

Is it a problem? Not really, though you won't be running any marathons. "Damn me!" as the English used to say. There is no feeling of drowning as experienced with emphysema. You'll just need to take things easy, slow down and pace yourself. It's not so bad. If you can still do what you want to do, need to do, if a bit slower, that's something to be thankful for.

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Bathing

Sure showering is fast and efficient, but there's more to life than speed and efficiency.

There is grace. There is pleasure. There is serenity. There is meditation.

If you have a bathtub that is shaped for comfort or a Jacuzzi, a long steaming soak submerged to your nose hovering between sleep and wakefulness does a lot to slow the heart, relax muscles, ease flank pain and just make life a little more pleasant on those cold winter days, whether or not you have PKD. Treat yourself to a good soak.

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Eating

You will find you won't be able to eat as much at once as you used to.

The solution? Snacks.

Contrary to what we've been taught, snacking is exactly what you need to do. Even the Mayo says [snacking can be healthy](#).

Snacks don't have to be junk. Carrot sticks, celery, cheese and crackers, fresh roasted almonds, garlic stuffed olives, fresh lemonade, leftovers, tuna sand on whole grain bread or a fruit smoothie with frozen bananas can all be snacks. So can a fresh smoked sausage or bread fresh out of the oven.

Eat too much at once and you'll feel bad. You may also experience acid reflux, which feels like you just drank acid, which is just about what you did. Like I tell my wife, these errors are self-correcting. You overindulge in a superb chocolate cake an hour before bedtime and regurgitate hydrochloric acid all night and next time you'll find it easier to resist.

Keep your meals small. Don't try to eat as much as you used to. Eat a snack when you're hungry. And

explain what's going on to your partner so they won't think you don't like their food.

Diet

They used to think reducing protein intake reduced kidney damage. [Now it turns out that the benefit of low protein only accrue to healthy kidneys](#). My guess is they'll eventually discover that eating a healthy diet of what you like doesn't hurt anything. So just eat what you enjoy and what makes you feel good and satisfied.

Sex

I'll try to make this as titillating and graphic as possible (and yet, tasteful) so as not to disappoint anyone.

Sex is fine as long as it doesn't compress cysts.

Well that about does it.

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Beware List

(A list of things that to do with care or not at all because they may compress cysts, causing bleeding, infections and other complications)

Anything that requires explosive muscular contractions

Physical contact sports—Your cage fighting career is over.

Hard physical labor—been trying to avoid that my whole life, now I have an excuse.

Jumping, jarring, falling and, more importantly, landing.

Bending over, tight fetal positions, twisting at the waist

Heavy Lifting

Weeding unless done on your hands and knees—this can really be fun as it gets you really close to the plants and bugs. Use a kneeling pad if you want to keep your pants clean.

Yoga positions that require compression of organs

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Deciding on Treatment Options

Okay, you've got PKD, there's no decision to make there. The coin's been tossed and you lost. [The chances are 50/50 if one parent has PDK](#).

But you do have a decision to make about how you want to proceed from here. It's your decision, and it's a big one: Do you opt in for treatment or do you not, and, if so, how much or to what degree?

Yes, despite what many fervently believe—and will not hesitate to tell you in no uncertain terms—you **do have a choice** whether or not to opt for treatments. It is neither illegal (yet, anyway), immoral, nor fattening to opt out.

I encourage you to consider carefully how you will live the rest of your life. Consider the costs, consequences and effects on both the quality and quantity of your life before you decide—because *there are costs—whatever your decision*.

If you opt in, treating PKD will become a very big part of your life. (Reading the forums makes me think that, for many, it IS their life.) It won't be fun. It won't be cheap. It won't be comfortable. However, it may, and I emphasize may, keep you alive longer. There are no guarantees, here.

Surgery

There are real downsides to every procedure. Surgical procedures are often the cause of pain [as bad as or worse than the original condition](#).

One of the biggest causes of postoperative pain is [adhesions](#). Heard of them? Most patients signing consent forms for surgery haven't either. I never had before I spoke to a surgeon about laparoscopic deroofing of cysts. [Many doctors seem to be unaware of them as well, leaving many patients undiagnosed](#).

What are they? They're the body's way of reacting to an injury, in this case, surgery. Adhesions can be bands or films of scar or connective tissue that forms in an attempt to protect organs that have been exposed to air, handled roughly, exposed to latex gloves, gauze, blood clots from surgery. [Laparoscopic surgery can cause less of them to form](#), but there's a catch according to my laparoscopic surgeon: You only get one try to correct a problem with laparoscopic surgery and then, after the formation of adhesions, traditional open surgery must be used, which—you guessed it—forms more adhesions.

What's [the problem with adhesions](#)?

They can pull on nerves and organs, causing:

- cramps
- abdominal pain
- pain during intercourse
- pain during exercise or stretching
- nausea
- vomiting
- back pain
- difficulty breathing

Keep in mind, these are the side effects of a surgery intended to correct cyst discomfort.

According to [an excellent article](#) in [The American Journal of Surgery](#), "...patients with post-operative [adhesions](#) may suffer from debilitating symptoms for years without knowing that their pain was caused by surgery."

How many patients recovering from major abdominal surgery get adhesions? [Just about all of them— 93%](#).
How many patients need surgery to correct the adhesions. Half of them.

How many patients need surgery to correct the surgery to correct the adhesions? [About a fifth of them](#).

If you opt for surgery, do it with your eyes open, understanding the risks and having a realistic idea of potential benefits.

Dialysis

Dialysis can help keep you alive, but that depends on what you mean by alive. Does living mean enjoying life?

As an aside... I just had a friend who had been on dialysis die today from kidney failure and he told me that, if he had it to do again, he would have opted out of dialysis. This guy was no sissy, either. I assume he had his reasons.

Here is [some of what you can expect](#) with the two types of dialysis:

Haemodialysis

- Fatigue
- dietary restrictions
- [restricted fluid intake](#)
- Low blood pressure
- Low blood pressure
- nausea
- dizziness.
- Invasive staphylococcal infections
- boils.
- sepsis or [blood poisoning](#)
- Muscle cramps
- Itchy skin
- difficulties falling asleep ([insomnia](#)) or staying asleep
- bone and [joint pain](#)
- lack of interest in sex [dry mouth](#)
- [anxiety](#)

Peritoneal dialysis

Lack of appetite and nausea
being sick
chills (episodes of shivering and cold)
fever
rapid heartbeat (tachycardia)
feeling thirsty
not passing any urine
Hernia
Weight gain

So, as you can see, dialysis can keep you alive, but at a cost in your quality of life. Keep this in mind when people become rabid when they learn you may opt out of a treatment.

Transplantation

How about a transplant? Isn't it like PKD kryptonite? Isn't it the holy grail of survival?
You decide.

[The average transplant lasts about ten years.](#) But, [one out of ten will fail in a year and 4 out of ten fail within 5 years.](#)

Not a sure thing, is it. So, all the expense, risk, pain and inconvenience and it's a flip of a coin whether you'll still have it in 5 years.

And transplant recipients require life-long medications with [side effects such](#) as:
(Keep in mind that this list was compiled by a kidney transplant surgeon—an honest one.)

high blood pressure
tremor
hair growth
overgrowth of gum tissue
increased cholesterol
damage to the liver or kidney (my favorite)
joint pain
blood cell depression
diarrhea,
acne
abdominal pain
vomiting
diarrhea
hair loss
development of a rounded face (it's true. I've seen it.)
diabetes
hypertension
joint problems
cataracts
stomach ulcers
weight gain

Well, that's it, the list of side effects from the medication you will be on for the rest of your life or until your transplant fails in an average of 10 or 12 years.

I would urge you to ask yourself this: will the time I have left be of a higher quality if I enter the medical treatment pipeline?

Many will find this question an uncomfortable one. They will follow their doctor's advice implicitly and without question if it promises a chance of longer life. This choice may be right for them.

Is it right for you?

Have the courage to at least ask the question—and consider carefully the answer.

Memento mori

Remember you will die.

Many people forget. They live their lives, squandering their days as if they will live forever.

They won't and neither will you or I. Nobody gets out of here alive. Our gut puppets have expiration dates built in. They contain the seeds of their destruction, which, after all, is the plan. We are meant to die. Just think if we didn't. Oi! Such a mess we'd be in!

Complications with PKD are as numerous as they are inevitable. PKD is going to kill you and I. Nobody seems to want to tell you that. It's considered "negative." I ask: how can truth be negative—or positive? It's just the truth. Isn't it?

No matter what medical procedures you undergo, no matter what pills you take, no matter what foods you give up, no matter how low you keep your weight, your blood pressure or your intake of sodium...

PKD will kill you.

This is your curse—and your blessing.

How so a blessing?

Yes, our days are numbered.

Yes, we have pain and limits to what we can do.

Yes, we will die younger.

But less can be more and I suggest that maybe life can be more precious to us than it was before—because of PKD. It has become so, to me.

Crosby's band, CPR, does a song called *Time Is The Final Currency* which has the lyrics:

Time is the final currency.

Not money, not power...

The time will come when you will give

Anything...

For one more hour.

True, isn't it? When the time comes, neither your Rolex, nor your Mercedes, nor your portfolio will save you.

Most folks walk around believing, living, acting as if they're going to live forever. They work at jobs they hate, spend time with people they can't stand, eat things they don't like—and don't eat things they do. Why? To live longer. Why? Because they fear death.

Once you've gotten past trying to squirm out of it and accept the fact that PKD is going to kill you, you're free. Free from the illusion, the pretense, that you will live forever.

Free from the need to work fiendishly gathering belongings and "wealth."

You know what will kill you. I love that. For me that changed everything.

I no longer plan years in advance. I take each day one at a time now. Every day I get up and thank the creator for that single day, the greatest gift any mortal has ever been given—one day of life.

I don't do stuff I don't want to.

Why should I? I don't have the time to waste.

I no longer pass up stuff I love, either.

If I want to read past bedtime I do.

If I can't sleep at 2 am I don't lie there. I get up, work and watch the sunrise and go back to bed after dawn.

If I want a third cup of high grown Assam tea I have it. (I know, I'm a raving iconoclast.)

I'm easier on myself, now, too. I cut myself a bit more slack.

I do what I love to do and I'm pretty good at it—at least when no one's watching.

I let the kid I was when I was five loose to do what he likes to do, as long as it doesn't hurt anybody, and he's having a hell of a time doing it. And when that kid you were feels joy, guess what—you do too.

Keep him locked up and it doesn't matter how rich or famous or respected you are, you'll still be miserable—because he is.

Why not give it a try? You may enjoy it.

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Planning

If you decide to place yourself under a nephrologist's care with a long term view to dialysis and transplantation, then you will need to plan ahead to prepare for that eventuality.

If you decide to opt out of some or all medical care, you still may want to plan for your future.

If you do not want medical intervention you should make your wishes clear to your loved ones and complete the necessary legal documents, such as a [living will](#), to insure your wishes are honored by medical staff.

And advance planning for one's death is also smart—in fact everyone should do so. [The Neptune Society](#) is a great organization that takes a large burden off of surviving loved ones at the time of your death. For a reasonable fee paid in advance, they handle everything once we die. All the surviving spouse or relative must do is call them. They collect the body, cremate, provide a death certificate and return ashes in an urn provided or spread them as you prefer.

And, finally, if you would find it reassuring to be able to make your “final exit” from life gracefully—on your own terms, and in your own time—if your health deteriorates rapidly, you may find [this book](#) as helpful as I did.

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To Do

What you want when you want.

Eat your favorite foods.

Watch the planets move, sunrises, sunsets, the phases of the moon.

Eat when you're hungry, not when it's time to eat.

Sleep when you're tired.

Rise when you feel like it.

Be content with what is.

Refuse to worry, fear or regret.

Grow a garden.

Laugh—at everything—I mean, why not? It's all ridiculous, isn't it?

Forgive.

Dream actively, remember and contemplate your dreams.

Nap.

Snack.

Learn the fine art of dawdling, puttering and dilly-dallying.

Daydream.

Talk to the creator, even if you're not sure anyone's listening.

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Last Words

Well, that's about it.

You've got some things to work through, to accept. It won't be easy, but you can do it.

You've also got some decisions to make and some planning to do. You will find your answer, your way to live and your way to die. Have the confidence to do both in a way that feels right to you.

And remember, right now, PKD and all, you've got all that anyone on this earth has ever had or ever will—today.

Use it well.

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