

MDJunction Cirrhosis Support Group

Newsletter



Who Are We in this Cirrhosis Group?

PEOPLE
HELPING PEOPLE

Visit or Contact us (please!) via:

www.mdjunction.com/cirrhosis

www.MySickLiver.weebly.com

E-mail: MySickLiver@gmail.com

We're also on



as MySickLiver

Our group is now more than 800 members strong! I (Dennis) think that is about 100% growth since I first joined in 2010! We should all be proud of our growth! I know that we are reaching a worldwide audience that is not just populations where English is the primary language! I know we have members all across the US and Canada, UK, Scotland, Ireland, Australia, Hong Kong, Japan and India.

Our mission statement (of the group) has always been "A community of patients, family members and friends dedicated to **dealing with Cirrhosis, together.**" as clearly stated in the heading of our webpages. I took the liberty of highlighting the key part of our mission statement that makes us a unique "entity" within the overall structure of MDJunction. There are over 700 different groups on MDJunction, all of which have different "key part" phrases in their mission statement.

I thought it would be interesting to talk about what type of people become part of our community. I am not talking about location, gender, race, creed or the other types of demographic information. Unfortunately there are no tools available from MDJunction to measure *anything* so we couldn't go there even if we wanted to!

OK, then you may ask, "What types of members *are* we going to talk about?" The way I see it, we have a couple of type groups that are interesting:

How our members and/or visitors interact;

- Vocal;
- Occasional Posters;
- Stealthy Visitors.

What our members' roles are with end-stage liver disease (ELD):

- Patients;
- Caregivers and Family Members;
- Survivors.

Our members:

- Ask questions;
- Provide information;
- Vent!;
- Share emotions (fear, anger, sorrow, anxiety, etc.)

Our members play the following types of roles:

Patients—these are members who either need information about some aspect of liver disease or are providing information to other patients based on their own experiences or their research efforts. There are other groups on MDJunction for specific liver diseases like [Fatty Liver](#), [Hepatitis B \(HVB\)](#) and [Hepatitis C \(HVC\)](#) that deal with more specifics of these particular types of liver disease.

Caregivers and Family Members—these are members who are either directly caring for a liver disease patient or have a family member whose loved one has cirrhosis and who needs to learn about the disease. *These members tend to have needs that are better supported in the MDJunction "Caregiver Online Support Group"*. Not only do caregivers need to understand about cirrhosis and other liver diseases, but caregivers need additional support to deal with issues such as stress, patient advocacy, grief, anxiety and other "tricks", often learned the "hard way" by other caregivers. Just as cirrhosis has over 90 different underlying causal liver diseases, caregivers are folks that have a common set of issues regardless of what their patient is suffering from. While we welcome caregivers in our group and don't want to restrict our members beyond what the "rules" of our group permit (no spam, no profanity, no mistruths, etc.), we do ask that caregivers respect that the primary purpose of the Cirrhosis Group is to help with end-stage liver disease.

Survivors—these are members who either have received a liver transplant or are the family members/caregivers of patients who passed from this horrible disease. I like to think that our experience gives us a different perspective and, most often, more solid information than the people involved in active end-stage liver disease may have. Speaking from personal experience, a transplant not only gives a second chance at life, but also instills a passion to "pay it forward" to help others going through the disease and promote the cause of organ donor registration.

Don't forget we also have other groups on MDJunction supporting underlying liver diseases:

[Alcoholic Liver Disease](#)

[Fatty Liver Disease](#)

[Hepatitis B](#)

[Hepatitis C](#)

[Hemochromatosis](#)

How Our Members and/or Visitors Interact

Not only are there several different *methods* provided by Roy and Anon as part of the features of MDJunction but the way that we utilize these features is one type of grouping our members. When we use MDJunction, we go beyond just being an individual—we become artists of sorts, with a blank canvas (discussion) that goes into a file system (forums) within our group. You don't *have to* go into the file to find the most recently active canvases. You can take any canvas out of the file to look at and maybe, if you (the artist) are a member of the group, even add your own input (reply) to the canvas. Hopefully all new member artists create a new canvas in the "Introductions & Personal Stories" forum. Our artists fall into the following categories:

Vocal—these are members who start new canvases or add their own input to another member's canvas on a regular basis. We are fortunate to have many, many long-term members that jump in to help others or discuss their own issues. My own observation is that "vocal members" seem to "stick" with the group until their situation changes—maybe they find a better group (I seriously doubt one exists if I may say so myself and I think many in the community agree!!) or their medical status changes like they received their transplant, they have a more critical illness to address or, unfortunately their cirrhosis takes them away from us. Of course some people just lose interest or their condition improves because their underlying liver disease had not yet become true cirrhosis.

Occasional Posters—these are members who seek information that may be on an existing canvas, which then leads to more questions that they add to the canvas. In the cycle of our membership, "occasional posters" often become "vocal" as they feel more comfortable with the group.

Stealthy Visitors—these are members or non-members who have not yet posted their own entries to any existing canvas and who have not even started their own canvas. This type of visitor is most likely trying to see what our group is all about, they may have their own question that they are trying to find an answer to or they might just be curious about cirrhosis. Sometimes they are looking for "End-stage Liver Disease" (ELD) because they may not yet know that ELD is cirrhosis.

What Our Members' Roles are with End-stage Liver Disease

Now, what role is a member when they come to our group? We really can't talk about what kind of roll our "stealthy visitors" may have in relation to cirrhosis—they haven't told us anything about themselves! Everyone else has some sort of direct connection to the horrible disease of cirrhosis with all of its symptoms, complications and treatment options.

"Things Every Caregiver Needs to Know"

A list compiled by Rene' Cantwell, CEO of [Families of Loved Ones](#). This article originally appeared on the now defunct (but mostly intact) Families of Loved Ones website and became a post in the [MDJunction Caregivers Group](#). The author ([Bkwrn398](#)) of the post talked, via email, with Rene' Cantwell and she graciously granted the author permission to share information from her website! Families of Loved Ones' newsletters and magazines are "designed to bring families together to maintain optimum quality of life through investigation, inspiration, planning and advocacy."

1. You Are Not Alone. Ask For Help

This may be new to you-but countless others (over 50 million in this country alone) are caregivers. Many have been successfully coping for as long as families have existed. The trick is to find those who do it well and be open to what they have to teach.

2. Be An Informed Consumer

Whatever the cause of your loved one's frailty, research and learn all you can about it and available services. Take advantage of discharge planning and home care services. Talk to professionals in the field, and let them guide you, but also use the Internet, and libraries to help you understand as much as possible.

3. Write It Down

Buy a small sturdy notepad or address book to log in names, dates and information. Always keep it with you because you never know when you will need to refer back for clarification or reach out to a contact person.

4. Brain Overload

Recognize that your abilities to concentrate, organize & delegate will be tested, and eventually strengthened as you decide to move forward.

5. Be Assertive, Not Aggressive

Learn how to effectively communicate with the professionals providing care for your loved one. Learn their names, keep notes so that you can ask direct questions and note the answers.

6. Do Not Assume That Directions Are Followed

We are all human. Reviewing any change in your loved ones care plan and or medications is essential. Make yourself available for care plan meetings-you will help the professionals understand your family dynamics, and you will learn of changes and recommendations. Follow through with all involved. Have the changes been implemented? Are those changes are having a positive effect for your loved one?

7. Designate One Family Member to be the Patient's Advocate

The professionals providing care will need one person to communicate with. All other family members need to support that person the best they can. Use this opportunity to come together; there is no time or energy for negative behavior, whatever your differences-put them aside.

8. Practice Listening

It's harder than you think, but by learning to listen you can shut off the chatter within you and open yourself to truly engage in what others have to offer.

9. Promote Independence within Proper Context

We all need to feel that we are in control of our lives. Imagine an event that would render you incapacitated to some degree. How would you feel if your advocate made your feelings and desires less significant than their own? Of course, proper context is the key. But always consider how you would feel in that person's place.

10. Maintain an Individual's Integrity

Do not project your feelings, wishes or intentions to your loved one. Presumably they have expressed their wishes previously; hopefully all legal documents are in order. Deal in fact, do your best to not make very important decisions when overwhelmed with emotion. Above all pray for grace, and nourish your sense of humor.

Practical Tips for Caregiving

A Population at Risk

63% of caregivers 60 years and older have a higher mortality rate than their non-caregiving counterparts. Between 40 and 70% of caregivers have clinically significant symptoms of depression. More than 22% of caregivers are exhausted when they go to bed at night (if they go to bed at all!) Caregivers are at increased risk for heart disease. Caregivers who experience chronic stress are at greater risk for cognitive decline themselves. Later onset depression is one of the newest risk factors for Alzheimer's disease!

Three Basic Beliefs

1. When you take care of yourself, the person you care for will also benefit.
2. You can "thrive," not just "survive" as caregivers.
3. You are not alone!

Stress

Even though we can't stop it, we can still manage it before it controls us! The longer we wait to identify what's causing stress--the longer it will take to recover from its effects.

Symptoms of Caregiver Stress

1. **Denial**—about the disease and its effects on the person who has been diagnosed.
2. **Anger**—at the person with Alzheimer's or others that no effective treatments or cures currently exist and that people don't understand what's going on.
3. **Resentments**—feeling overwhelmed our loved ones needs and feeling as though there is no time for ourselves.
4. **Social Withdrawal**—from friends & activities that once brought us pleasure.
5. **Anxiety**—about facing another day and what the future holds.
6. **Depression**—begins to affect the ability to cope.
7. **Exhaustion**—makes it nearly impossible to complete necessary daily tasks.
8. **Sleeplessness**—caused by never-ending list of concerns.
9. **Irritability**—leads to moodiness and triggers negative responses and reactions.
10. **Lack of Concentration**—makes it difficult to perform familiar tasks.
11. **Health Problems**—begin to take their toll both mentally and physically.

What are Your Warning Signs?

Examples of warning signs include forgetfulness, anger, headaches, stomach aches, sleeplessness, increased heart rate, back & neck pain, inability to concentrate.

Our beliefs often become a barrier for

action. Most often these beliefs are not based in fact, but we continue to let them control our lives.

Hidden Sources of Stress

- I am acting selfish when I put my needs first.
- I am the **only one** that can make Mom happy.
- No one can care for my spouse/family member the way I do.

Results of neglecting stress

- Increased health problems
- Disrupted relationships
- Burnout
- Depression
- Decreased quality of care

Effects of stress can be alleviated by:

- An assessment of family caregiver needs that lead to a care plan with support services.
- Caregiver education and support programs.
- Respite to reduce caregiver burden.
- Financial support to alleviate the economic stress of caregiving; and
- Primary care interventions that address caregiver needs.

First Steps

- Diagnosis
- Education
- Needs Assessment

Dementia is a blanket term used to describe cognitive impairment. There are many types of dementias. Alzheimer's disease is a diagnosis of exclusion and should only be given after all other organic considerations have been ruled out.

Assessing Your Needs

- What type of help does my loved one need to remain as independent as possible? This should include health care, supervision, in-home care, housekeeping, etc...
- How much money is available to pay for outside resources? What will our insurance cover?
- What days and times do I need help?
- What assistance can I provide myself?
- What types of help, if any, are my friends and family willing to provide.

Check Local Resources

- Information and Referral
- Adult Day Care
- Case Management
- Legal & Financial
- In-Home Care
- Support Groups
- Counseling

Wishing you the best of luck!

Kendra Micka, MSW, ACSW, Family Consultant, Del Oro Caregivers Resource Center
Borrowed from the [articles](#) section of the MDJunction [Caregivers Group](#)

What's It Like at Liver Transplant Time?

There are currently about 17,000 people in the US that are waiting for a liver transplant. The liver is the second most transplanted organ with kidneys being the most transplanted. Over 6,300 liver transplants occurred in 2011. It is clear that liver disease is a more common and more serious disease than most people realize.

There are over 90 different causes of cirrhosis. Alcohol; tainted blood transfusions or improper needle sterilization associated with tattoos or drug use; and obesity are the top 3 causes of cirrhosis but there are many more. Some underlying causal diseases are acute (short onset, but severe) as in Wilson's Disease requiring immediate transplant. Other underlying causal diseases are not curable by a transplant such as autoimmune diseases like PBC or such as blood borne viruses like Hepatitis B or C (HBV, HCV). A liver transplant is the only treatment available once liver disease advances to the extreme cirrhotic stage.

Many people cringe when they hear the word "transplant". I (Dennis) do and don't understand why this feeling persists! I *do understand* because of the nature of the process: it is probably the most invasive, non-emergency (usually) surgery that can be performed on our bodies. Major surgery has many risks right from the start of anesthesia until days or weeks following the surgery itself. Modern surgery is advancing on a daily basis, mitigating most of these risks, but still leaving some people who struggle to survive after the surgery.

What I *don't understand* is a candidate who does not want to acknowledge the risks associated with the surgery itself when they also recognize that life with a healthy liver would be so much better. Most cases of cirrhosis steadily advance to the point where your liver function has so deteriorated that your mortality becomes extremely short. That is how the system of liver allocation currently works. Most people don't rush in to the transplant process and are able to manage their cirrhosis quite well for a number of years.

So, you've been diagnosed with cirrhosis, your doctor (hopefully a *liver specialist/hepatologist*) has ordered extensive testing (an *evaluation*) to determine if you can be considered for a liver transplant (called a *transplant candidate*), your tests all came back positive or treatment of other problems can occur simultaneously with treatment for your liver and you are officially *listed with UNOS* as a candidate. What's next? It depends entirely on how sick your liver really is in relation to all the other candidates.

Let's skip to when your liver becomes the worst in your local or regional area as we have previously discussed allocation of available donor livers. You may not be aware that you have moved to the top of the list. Sometimes it is very obvious that you are in dire need of a transplant. More often YOU may feel like you are in dire need when, in fact, somebody else is in worse shape. Many candidates feel like they are managing their symptoms but they have moved up the list without really knowing it.

Regardless, the whole process begins with a phone call that can come at any hour of the day or night. There is no way to predict when a liver will become available. The candidate should always carry a cell phone or pager so that they are available when a liver becomes available. The first thing that the representative from your Transplant Center (TC) will do is to confirm they have reached the proper person, and then ask that you sit down

while they identify themselves. They will then tell you that a donor liver is available and ask if you will be able to get to the TC in the allotted amount of time (predetermined at the time of your originally listing). You must be absolutely honest in your reply as there is not extra time for the viability

of the available liver. If you are not able to arrive on time, give an honest answer so that the next person on the list has a chance to live. If you are able to get to your TC on time, the "timer" starts for both you and the urgency of recovering the available liver. Relax, the process is just starting-

-there is still some time before you are ready to prepare for surgery. If you are not already at the TC due to other circumstances, get to the TC center as safely and as quickly as possible. Do not drive yourself, as you will not be able to drive home following surgery.

It is best to take as few items as possible with you to the TC as you will not be in your own room until a few days after surgery. Do not bring any jewelry, including rings, earrings or bracelets. Do not bring a cell phone (or send it home with your caregivers). I had only the clothes I was wearing and a book to read while waiting for transport to surgery prep. The book and my clothes went home with my caregivers. I had a "go bag" ready to bring to the hospital once I was assigned my own room. The things I sent home before transport to surgery went in my go-bag when my caregivers got home. You will experience the following:

1. Registration: confirmation of demographic and billing information followed by direction to a temporary hospital room, usually in the "transplant ward" of the TC.
2. Change into hospital gown and wait until the available organ is retrieved and examined.
3. If the retrieved liver looks completely acceptable to your medical team you will be given another physical exam and many vials of blood will be taken for last minute testing, typing and cross match for both matching to the donor organ and to ensure there is sufficient replacement blood for use during surgery. An IV needle is put in place for use in the prep process. I had enough time to nap for several hours at this point but that is not always the case for other patients.
4. Further waiting until the surgery theater is ready and it is time for transport to prepare for surgery.

Before you are transported to surgery prep, you must not leave anything in the temporary room you were in and you may not bring anything along to prep. If you wear glasses or dentures they must be given to your caregivers so they don't get lost during the next few days. Believe me; you won't even notice that you don't have them!

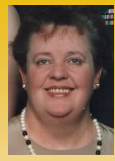
Surgical preparation is probably different but similar at every TC. All I can



speaking to is my own experience. When I went to the prep area, my IV started with what was probably just a saline solution to make sure I had the proper hydration levels. I remembered that a billion and a half questions were asked and answered. I was trying to stay warm (one of the problems with liver disease is that I was always cold, usually freezing). I was buck naked except for the discreet placement of a small towel. The whole time that I was conscious in the prep area there was a "zip-zap" plastic card embosser (like they used to use for credit cards—geez in a few years people won't know what those are!) running for all the labels, orders and other miscellaneous paper work that would be generated. I talked with a lot of nurses and anesthesiologists—everyone was super nice and doing their best to make me comfortable. They explained that they would be attaching some devices to my back to keep me warm during surgery—as if I would know anyway! They started the knockout juice as they started attaching these thick clay-like pads to my back. They felt warm, slimy and sticky. I don't remember a single *coherent* thought for several days.



CORNERS



Gail "mpmom"
Fatty Liver Disease

I am a wife and mother who wants people to have information available in a simple and understandable format. My quest to find information when I was first diagnosed with cirrhosis led me to create the site that is now "My Sick Liver dot com". I have had numerous health issues over the years and was finally diagnosed with cirrhosis as the result of fatty liver disease I also have diabetes and psoriatic arthritis. "My Liver may control my daily life but I am much more than my liver."

Hello everyone and welcome summer. Here it's hot really hot; the humidity is stiffening and sticky. Most of the year I'm cold and then the summer hits, I don't handle the heat very well it seems to increase my inability to stay awake. You would think in some one that normally has trouble sleeping that would be a blessing. But no, it's not a restful sleep; it's more of an inability to stay awake or to sleep. I can't keep my eyes open but as I dose off, I awake suddenly never getting more than a few minute at a time. But not

really being awake either. As the day cools then I'm awake again. Fall is my favorite time of the year and I can't wait.

News in the Fatty Liver World

"liquidz1" posted a link in the Fatty Liver Group to information on [a new clinical research study](#) being conducted by Immuron LTD, a publicly listed Australian biopharmaceutical company focused on oral immunotherapy using dairy-derived antibody products for humans. "Currently, there are no drugs proven to effectively treat NASH or fatty liver disease, and no approved products. The most effective known treatment for fatty liver is a combination of diet, exercise and weight control. For a time, weight loss drugs were being utilized in fatty liver treatment, however these obesity products have a poor safety profile."

Immuron is conducting a study on the effects of a new drug, IMM-124E, contains a natural ingredient, Bovine Colostrum Powder, which is harvested from Australian dairy cows immunized with Immuron's proprietary Lipopolysaccharide vaccine. "Clinical results demonstrated improved liver enzyme levels and improved metabolic parameters as well as lipid profile in treated patients."

It certainly looks promising as they are ready to summit to the FDA for trials in the US and Israel. If successful, the new drug will give new hope to preventing the progression of fatty liver to cirrhosis. For those that have already progressed to cirrhosis the possibility for stopping progression to liver failure may become a real possibility. New products take time to get approval (for good reason!) but this does appear safe during initial testing.

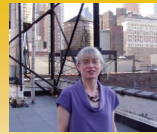
To me the most important thing to take away from the article at this time is the fact that research is being done. [Please take a look at the article.](#)

Thanks liquidz1 for posting the link!

Late Breaking!

Another company has a similar product announcement:

[Raptor Pharmaceutical Corp. Begins Dosing in Phase 2b Trial of RP103 for Non-Alcoholic Steatohepatitis \("NASH"\)](#)



Mo "IronCelt"
Hemochromatosis

Shortly after I got married and moved across country at the age of thirty-eight, I started getting lots of weird nonspecific, invisible symptoms. When my hair starting falling out, I had something to show a doctor. I was soon diagnosed with severe hemochromatosis, at age forty, and cirrhosis six months later. I have now been dealing with these

there are the true terrors: the semi-organic, undead-zombies that are viruses.

Neither I nor any family member or roommate could've predicted my current germ phobia, for I was always comfortable with a bit of grunge around the edges of my existence. I no longer remember how I discovered that in an eight-month period after diagnosis, my white blood cell (WBC) count had dropped to about 40 percent of the normal level. My hepatologist answered my questions about this development, and I had to forgo the plan to accompany my husband on a six-month working trip to a country with notoriously inadequate sanitary infrastructure.

It was after he left that the infections started. First came the fungus. I still couldn't add two and two to figure out that the fungal infection was the result of compromised immunity and that it wouldn't go away with one or even many rounds of medicine. Then I arranged for a weeklong visit with my husband in a "suitably clean" developed country. I thought I would be safe from the mini-monsters there, but being a Supreme Ignoramus, I had somehow overlooked the fact that mini-monsters love to hitchhike. My poor spouse hauled whole families of microbes on his person, halfway across a continent. With insufficient numbers of WBC guards on duty, the migrant microbes rejoiced upon reaching my unprotected shores. My week overseas was a misery punctuated by confusing trips to chemist shops and pharmaceutical counselors.



It was during that Year of the mini-monsters that my hepatologist ordered up vaccines for hepatitis A and B—critical measures for anyone with liver issues. Two rounds of each vaccine, and one is set for 20-25 years' protection from those particularly nasty viruses. I now also use hand sanitizer after touching anything or anyone outside my home. I've still caught two colds in the last four years, and their severity and the horrendous secondary bacterial infections remind me of the importance of staying well.

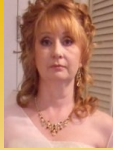
But nothing seems to keep the fungus at bay except continuous use of topical agents (the oral medications damage the liver). Early on, when my then-family doctor hadn't yet figured out how "special" I was, I apparently acquired a nonstandard species of fungus, one that didn't register on the usual test. Because I "failed" the test, the doctor canceled my prescription. A day or so later, I began to develop pain in my feet, and then enormous, painful red welts appeared, from my feet to my hips. I looked like I'd been stung by giant bees or pounded with the big steel hammer from the old Soviet logo. The ER physician informed me that I had erythema nodosum, a fairly rare condition. The "official" cause was never identified, but it was likely the result of a toxin produced by the off-brand fungus.

As all children, storytellers and filmmakers know, it's the monsters you can't see that are the scariest.

Mini-Monsters, Inc.

In previous issues, I shared some zoomorphic views of my doctors and myself and the legendary beasts I morphed into when afflicted with various cirrhosis-affiliated ills. The beings that really fill me with terror, however, are the mini-monsters: the invisible-to-the-naked-eye beasts like bacteria and fungi. And then





Marg "sadyllstillsane"
Primary Biliary Cirrhosis

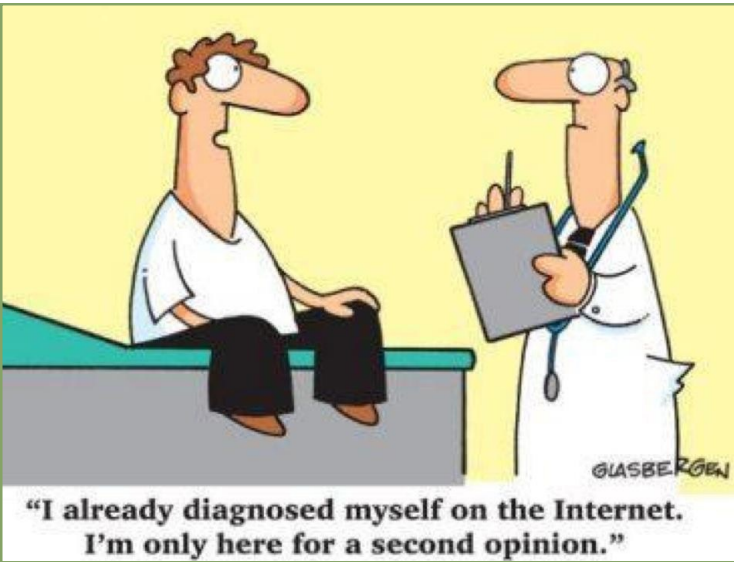
I am a wife and mother with Primary Biliary Cirrhosis. I have three kids; Kelsey is my daughter and Ryan and Linsey are my boy and girl twins. My husband Doug and I have been married since April 8, 2011. I worked with federal inmates who had been granted parole until taking disability leave in January of 2012. I live in sunny Saskatoon Saskatchewan, a beautiful city which I love. I have three great doctors and one bad liver. I have found over the last year or so that it is the little things, and the people I love that matter most, and I am not ready to let go anytime soon..... :)

What I Know

I know a lot more than I used to. In part, thanks to the Internet. I cannot imagine what it would have been like to receive this diagnosis in the days where all the information came either from the mouth of the doctor or a long session in the library. Today I have the convenience of turning on the computer and asking it to teach me about my illness.

In fact, when I was diagnosed with Primary Biliary Cirrhosis the gastroenterologist did not tell me much at all, he said to talk to my family doctor and look on the Internet for information. I went back to work that Monday feeling that I had nothing more serious than a wart and headed for my desk. I pulled the words into the computer and bingo....a lot of hits. I stuck to well respected sites like the Canadian and American Liver Association, PubMed, NIH, Mayo Clinic...but as I read the picture looked bleak. I was ticking off the symptoms as I read them and felt weak when I read "average survival is ten years post diagnosis". Within the first week I came to the conclusion that I had less than a year to live. Within the first three months after I was diagnosed I got busy.

I made a new will. I hired a firm to manage my estate. I signed a Power of Attorney. I drew up a Health Care Directive. I wrote letters to my children. I decided to marry my partner. I told most of my friends and relatives I was ill. I found MDJ. Then I sat back and waited to die. I had every symptom I had read about. I could not believe I wasn't being given a new liver on the spot. I couldn't believe the doctors were not panicked at what was happening to me.



I found ascites, check. I found Palymer Erythmia, check. Spider Nevi, check. Terry's Nails, check. I found HE, check. I clearly had a decompensated end stage liver and no one was noticing. I had my doctor do an ultrasound that said my liver was normal. I had blood tests that were not encouraging in their numbers and took it as a sign of impending doom. I was not a lot of fun to be around right after my diagnosis. I was told by my primary doctor that likely my disease was in its early stages. I was told by the gastroenterologist who diagnosed me little of anything. I was however slated for a biopsy. I spent hours on the Internet researching my illness, cirrhosis and livers in general.

And in retrospect what I mostly found, was that for me a little information goes a long way. I genuinely had symptoms no doubt. I was confirmed by biopsy at three months post diagnosis to be stage 3-4. Some parts of my liver showed fibrosis, other parts cirrhosis. I was ill there was no question. However, one thing I know now is that I was not as ill as I

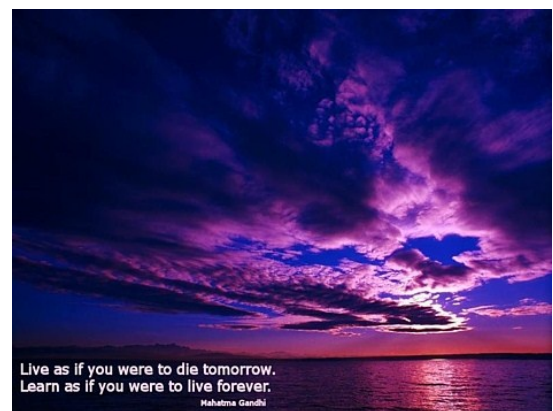
thought I was. In part, I had been seduced by the Internet into believing every symptom was my own and diagnosing myself with a grain of knowledge about a disease that volumes have been written about. When I was referred to my Hepatologist, I went knowing he would tell me it was all going to be over soon.....

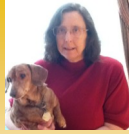
And he said he thought I could get five years before a transplant was necessary. He said I could and should keep working. He said he would monitor me. And I found out that monitoring and living a healthy lifestyle was all I could do. All the reading and teeth gnashing in the world was not going to change things. I had some genuine symptoms but I also was finding symptoms where there were none, or attributing meaning to symptoms that was not realistic. The first time I found xanathalasma on my eyelids I said to myself "this is end stage liver disease". Well, yes and no. Stage 4 (cirrhosis) is the end of the stages of liver disease. But it does not mean my liver is decompensated nor does it mean death is imminent. But it took me about a year to figure that out.

Today I have the security of a firm diagnosis. I have had adequate professional testing and consultations to be sure of the stage of my illness. I have a wealth of symptoms from that illness. But I also have other things going on in my body that are not related to my cirrhosis, the PBC or are in any way affecting my liver. I have come to learn that a decompensated liver and my stage four illness are worlds apart. I no longer think I will be dead within a year. Well, I outlived the first year so I guess that self-diagnosis was incorrect. Now, I look at the Internet to learn but I do not automatically apply all that knowledge to myself. I use it to be informed about my disease and to ask intelligent questions of the professionals who know far more about my liver than I ever will. I trust that I have learned enough to ask questions, and I have learned to trust the answers I am given.

I no longer worry so much about my scores, or stats. I know my liver isn't doing very well, but I also know I am not a death's door. I have had the virtual pain and pleasure of watching a virtual friend go from death's door to health. I know now that I can trust myself and my medical team to know when my liver decompensates. It won't necessarily be reflected in my ALP but it might. I may not ever have a sky high bilirubin, but I might. I may never bleed, go into a coma or need a TIPS or parenthesis to remove my ascites. But I might. Whatever way it goes, I now feel secure enough to believe that no number in the world will be the singular predictor of how my illness will progress. I know for sure it will progress. I know for sure where it is now, in general terms. And today that is enough knowledge. I cannot continue to torture myself with every bump and bruise, worry about every singular numerical increase in my liver enzymes or chase for symptoms like bumps on my eyelids. Those aren't the things that are going to make or break this disease for me. They may annoy me and side track me, but they aren't medical emergencies. I know what a medical emergency is for me now. I am lucky not to have had one.

So while I value the Internet for its knowledge and certainly for its ability to provide me with a wealth of support and friendship I have come to learn that I am one of those people who does not necessarily need to know a lot. I need to trust. I need to be educated. But I need to let go of obsessing about this. It stops me from living my best life while I have it to live. I know for myself that what I know best now, is that I need to stop seeking complications where none exist. *If I have to have cirrhosis, I do now know I do not have to let it have me!*





Susie "dachsiefan"
Cryptogenic
(Idiopathic) Hepatitis

I am a married woman who was first diagnosed in 1990 with giant cell hepatitis that evolved to cirrhosis. In 2008, I developed HE and edema. In 2011, I had the TIPS procedure to remove a portal vein clot and restore blood flow. I am currently on the UNOS waiting list for a liver.

Choosing Insurance Coverage to Supplement Medicare for Pre and Post-Transplant Care

Many of us who have cirrhosis (end-stage liver disease aka ELD) qualify for Medicare because of our age (65 and over) or disability. Disabled individuals become eligible for Medicare two years from the declaration date of disability specified in the application for disability.



Medicare Consists of Several "Parts"

Part A: Hospital Coverage

Part B: Medical Coverage

Part C: Replaces Part A, Part B and usually Part D with private insurance that may be more comprehensive than regular Medicare coverage. Also known as "Medicare Advantage" Coverage and should not be confused with "Medicare Supplement" Coverage (Medigap).

Part D: Prescription Drug Coverage

Medicare also covers some preventative procedures once a year or once every two years. If you had a mammogram June first of 2011, make sure you don't have your 2012 mammogram before June 2; otherwise Medicare will not cover the costs. Also, there has been a lot of confusion regarding wellness exams. You are covered for an annual wellness exam as defined by Medicare but not an annual physical. Make sure your provider's wellness exam matches Medicare criteria.

Part A covers inpatient hospitalizations up to 60 days after the initial deductible per benefit period. A "benefit period" is the time between your admission and the date of your most recent hospital release. A new benefit period starts if you are hospitalized 60 days after your last hospitalization. For example, if I was admitted on January 1 and was hospitalized again on February 14, these two admissions would be during the same benefit period. If I was released March 1 and was admitted the following August, this admission would trigger a new benefit period, and another Part A deductible would be assessed. If the hospital stay exceeds 60 days, I would be responsible for copays until my lifetime reserve days are exhausted. Then, I would be responsible for all costs each day. For inpatient care in a skilled nursing facility, hospice care, home health care a religious, non-medical health care, psychiatric hospital see the publication **Medicare and You** from The Centers for Medicare and Medicaid Services, 2012.

Part B covers 80 percent of doctor, lab and outpatient providers who accept assignment for covered services. Medicare sets an annual deductible, which may be deducted directly from your SSI or SSDI payment. Please note the word "covered". If Medicare does not cover or may not cover a visit, test or procedure, you should receive an Advance Beneficiary Notice (ABN) that they will ask you to sign. If you sign the form, you are taking responsibility for paying for the test or procedure. I have had to sign ABN's for many blood tests including my monthly INR and tumor/cancer antigen tests when scans have shown my lesions have grown. I have had to appeal several of Medicare denials with letters of medical necessity from my physician or a corrected diagnosis code. Thus far, I have been successful in getting Medicare to reverse their denials, but it takes a lot of time and perseverance that can be difficult when one is dealing with the effects of liver disease. Remember that you need to watch your Explanation of Benefits (EOBs) very closely and become a strong advocate of your own health rights.

Part C ("Advantage Plan" Coverage) is another Medicare health plan choice you may have as part of Medicare. Private companies approved by Medicare offer these plans. If you join a Medicare Advantage Plan, the plan will provide all of your Part A and Part B coverage. Medicare Advantage Plans may offer extra coverage, such as vision, hearing, dental and/or health and wellness programs. Most include Medicare prescription drug coverage (Part D).

Medicare pays a fixed amount for your care every month to the companies offering Advantage Plans. You must pay an additional premium to the insurance provider. These companies must follow rules set by Medicare. However, each Advantage Plan can charge different out-of-pocket costs and have different rules for how you get services (like whether you need a referral to see a specialist or if you have to go to only doctors, facilities or suppliers that belong to the plan for non-emergency or non-urgent care). These rules can change each year.

Part D coverage pays for prescription medication that you receive outside of a hospital. Part D plans vary in monthly price and the drugs they cover. There may be an initial deductible you must meet. The initial coverage phase is where all your drugs are covered by insurance and you pay a pre-set copayment. The coverage gap phase or so called "donut-hole" is where you have to pay 86% for generics and 50% for covered name brand drugs up to your total annual drug cost of \$4,700. Then, the catastrophic phase starts and you pay a small coinsurance or copayment of drug costs until the end of the year.

Medicare Supplement Insurance (Medigap) policies are health insurance sold by private insurance companies to fill gaps in Medicare coverage. Medigap policies can help pay your share (coinsurance, copayments or deductibles) of the costs of Medicare-covered services. Some Medigap policies also cover certain benefits Medicare doesn't cover. Medigap policies don't cover your share of the costs under other types of health coverage, including Medicare Advantage Plans, Part D Plans, employer/union group health coverage, Medicaid, Department of Veterans Affairs (VA) benefits or TRICARE. Insurance companies generally can't sell you a Medigap policy if you have coverage through Medicaid or a Medicare Advantage Plan. Your monthly cost is dependent on the amount of supplemental coverage you select and either your age if you are 65 or over or the disabled rate if you are younger than 65. Medigap insurance companies in most states can only sell you a "standardized" Medigap policy identified by letters A through N. Each standardized Medigap policy must offer the same basic benefits, no matter which insurance company sells it. Cost is usually the only difference between Medigap policies with the same letter sold by different insurance companies.

What are the Differences between Medigap & Advantage Coverage?

Private insurance companies offer both, and both help to cover the gaps of regular Medicare. Medigap refers to a group of supplemental insurance plans that work in conjunction with your regular Medicare benefits. In contrast, Medicare Advantage plans are separate from Medicare. In fact, if you purchase a Medicare Advantage plan, you are de-enrolled from Medicare. Following are some more key differences:

- Medicare Advantage plans must provide at least the same coverage as Medicare A and B, but vary widely beyond this minimum set of benefits.
- Medigap plans offer services from a large network of doctors and care-givers, while the services offered by Medicare Advantage plans are usually in a restricted network.
- Medigap plans always require an additional monthly premium.
- The premiums for Medicare Advantage plans are often less than those for Medigap plans, and in some cases there are no monthly premiums for Medicare Advantage plans.

To determine which type of policy is best for you, visit Medicare.gov. At this website you can search for Medicare related plans that are available in your area. Make sure to review the "Drug Formulary" for the plan that you consider to make sure it covers all your current medications and probable post-transplant drugs. You can get a list of post-transplant drugs from your transplant center. Check with your state's high-risk sharing pool insurance—some will help with the cost of drugs in the "donut-hole" period.

If you are having problems sorting through your options, seek the advice of your transplant social worker, a relative or close friend or a Medicare counselor. Many states offer free counseling for seniors and disabled people who are new to Medicare. Check with your municipality, county health department, local senior center, park district or library to see what is available in your area.



**Dennis "dmanflan"
Liver Transplant Recipient**

I am a father, grandfather and husband for more than 38 years who will be eternally grateful to my family for sticking with me during my dark days. I have such a spark in me to try to return as much effort that I can to support many transplant related areas as possible. I love to give my opinion on these topics!

I received a new liver in July of 2008. I destroyed my native liver with alcohol developing cirrhosis with portal vein thrombosis (PVT) and eventually hepatocellular carcinoma (HCC). I had been completely sober for almost 2 years before my transplant.

Finally Getting Sober

Some people can stop drinking on their own, while others need medical supervision in order to withdraw from alcohol safely and as comfortable as possible. Which option is best for you depends on how much you've been drinking, how long you've had a problem and other health issues you may have.

What are the Physical Effects of Getting Sober?

When you drink heavily and frequently, your body becomes physically dependent on alcohol and

goes through withdrawal if you suddenly stop drinking. The symptoms of alcohol withdrawal range from mild to severe, and include:

Headache	Shaking
Sweating	Nausea or vomiting
Anxiety and restlessness	Stomach cramps and diarrhea
Trouble sleeping or concentrating	Elevated heart rate and blood pressure

Alcohol withdrawal symptoms usually start within hours after you stop drinking, peak in a day or two, and improve within five days. But in some alcoholics, withdrawal is not just unpleasant—it can be life threatening.

Call 911 or go to the emergency room if you experience any of the following withdrawal symptoms:

severe vomiting	confusion/disorientation
fever	hallucinations
extreme agitation	seizures or convulsions

The symptoms listed above may be a sign of a severe form of alcohol withdrawal called delirium tremens, or DTs. This rare, emergency condition causes dangerous changes in the way your brain regulates your circulation and breathing, so it's important to get to the hospital right away.

Do I need to go to detox?

If you're a long-term, heavy drinker, you may need medically supervised detoxification. Detox can be done on an outpatient basis or in a hospital or alcohol treatment facility, where you may be prescribed medication to prevent medical complications and relieve withdrawal symptoms. Talk to your doctor or an addiction specialist to learn more.

What Else Do I Need to Do to Achieve Long-Term Sobriety?

While getting sober is an important first step, it is only the beginning of alcohol recovery. Rehab or professional treatment can get you started on the road to recovery, but to stay alcohol-free for the long term, you'll need to build a new, meaningful life where drinking no longer has a place. Your will need to:

- **Take care of yourself.** To prevent mood swings and combat cravings, concentrate on eating right and getting plenty of sleep. Exercise is also key: it releases endorphins, relieves stress and promotes emotional well-being.
- **Build your support network.** Surround yourself with positive influences and people who make you feel good about yourself. The more you're invested in other people and your community, the more you have to lose—which will help you stay motivated and on the recovery track.
- **Develop new activities and interests.** Find new hobbies, volunteer activities or work that gives you a sense of meaning and purpose. When you're doing things you find fulfilling, you'll feel better about yourself and drinking will hold less appeal.
- **Continue treatment.** Your chances of staying sober improve if you are participating in a support group like SMART or AA, have a specific individual to go to when you need help with or a guide to the program or are involved in therapy or an outpatient treatment program.
- **Deal with stress in a healthy way.** Alcohol abuse is often a misguided attempt to manage stress. Find healthier ways to keep your stress level in check, such as exercising, meditating or practicing breathing exercises or other relaxation techniques.

My Experience with SMART Recovery® and Rational Recovery®

At first it was extremely difficult to live with an unfulfilled dependency. After many years of counseling and trying various means of getting straight including AA, it turned out the only method that really works is a self-commitment to experience life as it really is and not look for any *non-rational* means of escape. Somewhere in my journey I had heard about an alternative recovery program called "Rational Recovery" and later "Smart Recovery".

As it turns out, both of these programs have an extensive online web presence (see links below). I spent many hours perusing these sites and came to agree with the premise that only I am responsible for my actions and only I can make any changes to my behavior. It does me no good to try to blame anyone or anything else for what I decide to do—I'm way too smart try to hide from myself.

I had already gained "a lot" of experience with the physical side of getting sober but could not maintain my resolve to *stay* sober. I started really working at understanding what it was in my personality that made me behave the way that I did when I knew my actions were physically destructive. That simple step of recognizing that my behavior, being something that I thought I should be able to control, was the key to understanding what type of help I really needed.

I read through all the information on Rational Recovery's and SMART Recovery's websites. I was almost immediately interested in the methods and philosophy of both programs. I eventually used the methods of both programs to change my own basic philosophy on drinking. It started with a simple commitment to myself: "I will never drink again!" Easier said than done at first but I just kept repeating it to myself over and over again.

In a matter of days I expanded the commitment to "I will never drink again and nothing will ever change my mind!" Now came the real work of the program: learning, actually quantifying my reasons for not needing to drink anymore. I learned there were certain situations when or where I would normally drink. If I gave in to my desire to consume I knew there would be certain consequences for my behavior. It became easy to focus on just how sick I had been up to and through my self-administered final detox and then recognized that I never wanted to go through that ever again.

I gained personal satisfaction in knowing that I was putting more and more time between that last drink and where I was at in the timeline of my recovery. I can't say that I felt much better—I was well past simple alcoholic liver disease and approaching decompensated cirrhosis. I didn't really know anything about livers at that time other than the fact I had really done a number on mine! I still slept a lot but my family thought I was just passed out again. My diet didn't really change, eating very little and not the right types of foods either. In retrospect I should have had a supervised re-entry to the world without alcohol

Pertinent Links:

[Alcoholics Anonymous® \(AA\)](#)—Developed over 65 years ago by a small group of alcoholics, the AA program provides simple tools for living based on a set of "spiritual principles" and a reliance on the fellowship of men and women who share their experience and offer support as part of a life-long process of recovery. AA is a twelve-step program for people in recovery from alcohol abuse. The site provides an online list of central offices and groups in the U.S. and Canada, meeting contact information, a description of the 12-steps and traditions, a listing of AA literature and a bulletin board.

[SMART Recovery® \(Self-Management and Recovery Training\)](#)—an organization providing free self-help support groups to people who want to abstain from addictive behavior. The program is based on cognitive, behavioral and educational methods that seek to change the beliefs and attitudes that can lead to addictive behavior. There is no religious or spiritual component to this method of recovery. The site has online recovery meetings, a message board, Internet discussion groups, a meeting list and recommended reading.

[Rational Recovery®](#)—is the concept of immediate self-recovery from addiction through the learned skill of planned abstinence. Abstinence is facilitated by using an easily learned method called Addictive Voice Recognition Technique® (AVRT). There is no religious or spiritual component to this method of recovery. The web site offers an online course on AVRT, an online bookstore offering Rational Recovery books, audio tapes, videotapes, discussion forums, articles and essays.

Guest Writer
MoonWatcher

Last month a new group was added to MDJunction to deal with liver disease issues related to Alcoholic Liver Disease (ALD) one of the major underlying liver diseases that result in cirrhosis. Already we have had some great posts in our new group!

What I've Learned about Alcoholic Liver Disease

Over at the MDJ Cirrhosis forum, I noticed an increasing number of new members joining the cirrhosis group in hopes of learning more about alcoholic liver disease. The posts usually go something like

this: "I was a heavy drinker and now I'm really sick and scared. These are my symptoms... Do I have cirrhosis?" I first joined the cirrhosis group with these same questions and after nearly a year of learning and research, thought I might share what I have learned.

It is important for anyone asking these questions to realize there are three possible scenarios you might be dealing with.

Scenario #1: Post-Acute Withdrawal Syndrome or PAWS

If you've been drinking heavily for an extended period of time and have never gone through detox before, the protracted symptoms can be quite disturbing indeed. I thought all alcohol withdrawal might entail would be a couple of shaky anxious weeks, followed by lots of willpower to avoid a relapse. Nothing prepared me (and I don't think anything could) for what I was about to experience. What shocked me most of all were the new symptoms I never had while drinking that began popping up once I got alcohol free.

Depression, Anxiety, Anorexia, Brain Fog, Liver Pain and a profound sense of Foreboding, all combine with a heightened sense of physical symptoms that make up the syndrome known as PAWS or "Post-Acute Withdrawal Syndrome". This is unfortunately a NORMAL part of the detox process that typically lasts for 3 to 6 months following initial withdrawal from alcohol. I was astonished at how much worse I felt, even after several months of sobriety, and assumed it was the beginning of the end for me.

One reason I found for the profound effects of PAWS is that alcohol is actually a rather powerful immune suppressant, and during withdrawal the immune system comes roaring back causing inflammation in the liver to increase for several months into the recovery process. Many doctors have noted that during alcoholic recovery, health often declines for a period of time before improvement is seen.

This may also explain why the health of recovering alcoholics can nose-dive into alcoholic hepatitis if the drinker relapses early in the recovery process. Pouring alcohol back into a liver with a heightened immune response going on can cause a metabolic train wreck to occur. Perhaps this is why some say recovering alcoholics become "allergic" to alcohol. I thought the alcohol/allergy thing was silly until I detoxed and experienced a dramatic increase in liver pain that spread half way across my lower chest for several months. I can only imagine what might have happened if I had relapsed during this time.

Scenario #2: Acute Alcoholic Hepatitis!

Acute Alcoholic Hepatitis occurs most often chronic drinkers who go "off the deep end" with alcohol, often for even a remarkably brief period of time. With chronic alcohol consumption a drinker's tolerance for alcohol increases, and this tolerance enables the drinker to consume enormous amounts of alcohol.

Typically, during a period of personal/emotional distress (all too common in alcoholism!), alcohol consumption will increase dramatically, to a point where the drinker becomes too sick to eat properly. Malnutrition is a potent trigger for alcoholic hepatitis, and is often mentioned in medical journals in diagnosis of AAH (have you been eating? can you keep food down?) and as an indicator of prognosis. If you can get these patients eating again, they typically survive, often with a full recovery. If you cannot get them back on solid food early in the recovery process, this is a BAD SIGN.

Needless to say, a relapse back into alcohol during recovery from alcoholic hepatitis is how many alcoholics meet their end. They get released from the hospital shaken and sick, and often on prescribed benzodiazepine drugs. A relapse at this point often precipitates a sharp decline in health, or sudden death from relapsing on alcohol while benzodiazepine drugs are still in your system.

Recovery from alcoholic hepatitis is a long slow climb, but if you survive the initial health crisis, the prognosis is generally good!

Scenario #3: Fibrosis and Cirrhosis

The first thing that goes through the minds of all alcoholics as they deal with symptoms of PAWS or recovery from alcoholic hepatitis is: "Surly I must have cirrhosis... There's no way I could feel this bad if I was not dying from alcoholic liver disease".

The depression and anxiety of PAWS often cause an obsessive brain loop of these thoughts of doom to occupy your mind continuously for many months during recovery, even when doctors assure us no signs of major permanent damage (cirrhosis) are evident at this point. While it is certainly possible your worst fears are in fact true, the odds are against this.

Statistically, only 10 to 20 percent of lifetime heavy drinkers actually die of cirrhosis, and these statistics include those with predisposing medical conditions. These predisposing conditions include: Past or current viral hepatitis (A, B or C), HIV infection, diabetes and/or severe obesity, hemochromatosis (iron overload), chronic use of prescription and/or some over the counter and recreational drugs and supplements; and last but not least, previous bouts of alcoholic hepatitis and/or alcoholic detox and relapse.

The connection between repeated bouts of alcoholic illness, recovery and relapse with cirrhosis is so strong it was long thought by many doctors that alcoholic cirrhosis could not even occur without this medical history being present. This theory has since been disproved, but this type of history is still the biggest red flag in diagnosing alcoholic cirrhosis.

If you don't have any of these predisposing conditions, it would be unusual (though not impossible) to see advanced cirrhosis occurring during an initial (1st time) alcoholic crisis/recovery. Be patient, don't panic, this too shall pass! If you do have one or more of these predisposing conditions, it might be wise to explore additional diagnostics if your symptoms do not resolve after several months of recovery.

Liver Fibrosis is a different matter altogether, and most chronic drinkers have some established fibrosis that will be with them for the rest of their lives. As disturbing as this may sound, mild to moderate fibrosis is usually quite benign, and shouldn't reduce life expectancy in a substantial way. Moderate to advanced fibrosis may be visible on ultrasound, where it may be described as a "coarse echotexture" of the liver. In alcoholic fatty liver disease, the fat is usually evenly distributed throughout the liver tissue, creating a bright echo or echogenic liver. When this bright echo becomes "coarse" it means the texture of the liver tissue is no longer even and there are areas of "something else" (fibrosis) interspaced with the normal tissue.

Again, even substantial fibrosis is not cirrhosis or a death sentence, and as long as you can STOP THE PROGRESSION of disease, you should be able to go on your merry way and live a long and normal life. Our bodies aren't designed to last forever and everyone experiences wear and tear of some form or another along the way.

What's the difference between substantial fibrosis and cirrhosis? Well aside from the problems advanced fibrosis can cause, at some point in the disease process specialized cells in the liver called "Kupffer Cells" apparently become alarmed at what is going on and begin secreting "inflammatory cytokines". These cytokines are supposed to accelerate damage control and regenerate the liver when it is injured. Unfortunately, when damage is widespread, this process also generates more fibrosis and a chain reaction of inflammation and formation of additional fibrosis occurs. Once this process gets started, it is very difficult to stop, and this is what I understand alcoholic cirrhosis to be—a state where healing and positive regeneration becomes a progressive inflammatory condition that results in liver tissue eventually becoming completely replaced by fibrosis and scar tissue.

Don't push your luck guys... Alcoholic Liver Disease is a Bear Trap one doesn't easily escape from but it can be done if you can get free from alcohol before it's too late. If you've stumbled into this trap, then GodSpeed, and best of luck to you.

Always remember you are not alone. Millions have gotten free, and so can you! The secret is to keep trying. Leaving alcohol was the hardest thing I ever did, but to my surprise I found there was life after alcohol, and it isn't all that bad. Perhaps I'm not dying after all.

Tips & Tricks

Recently a member of our support group posted a list of tips for people who are new to cirrhosis. It reminded us that there are many things that we may take for granted or really just forget about to help us manage our disease. Here is that list that we borrowed from [thatcrazyliv](#), adapted it for general cirrhosis and combined with information from [our group's website](#). Thanks thatcrazyliv!

Avoid anything and everything liver toxic as much as possible.

- Get a liver doctor (hepatologist): a good one will help you manage your medicines, adjusting for your percentage of liver function, and telling you the risk of taking some medications. Take that risk seriously: you will die without a liver.
- Get immunizations for Hepatitis Viruses A and B: the last thing you need is a viral punch to the liver.
- Avoid Acetaminophen (Tylenol®): this medication can further injure the liver in people with cirrhosis. The exact amount of acetaminophen that is safe in cirrhosis is uncertain; some experts recommend that patients not use more than 650 mg per dose every 4 to 6 hours, with no more than 2,000 mg per day. However, *even low doses may not be safe for those who drink alcohol*. Always discuss your use of acetaminophen with your health care provider.
- Look up all the odd things that damage livers: too much iron, too much copper, too much vitamin A. Chocolate can be bad in some cases.

Remove the cause of your underlying liver disease:

- For NASH, NAFLD and fatty liver: slowly and carefully reduce your weight. Even if you do not have diabetes, reduce your sugar intake. Insulin resistance causes inflammation in liver cells. Careful here: your liver takes a beating losing weight fast and fat cells store toxins that enter your system as the fat is converted into energy.
- For ALD: Stop drinking anything, forever! Easier said than done but it is your only hope of stopping the progression to cirrhosis. Find a program that works for you.
- For HCV and HCB: Find a treatment program that works for you with any other issues you may be dealing with. There are many new programs, some experimental, that have been very successful in clearing the virus from your system.

Diet

- Your doctor may put you on a low sodium diet, especially if you are having problems with fluid retention.
- Eat a balanced diet with adequate calories and non-red meat protein. Malnutrition is a major problem for cirrhosis patients.
- Switch to all the fruits and veggies you want (watch the sugar content in fruits).
- Have several, small low fat portion of protein per day. Your body needs protein to operate properly. Yes, lower protein causes your body to retrieve stored protein from fat cells but too little protein robs the short-term needs from the body, which causes muscle wasting before fat conversion, as it is an easier source of protein. Remember that your heart is a specialized muscle and can also be impacted.
- Diet under direction of a doctor or dietician if possible, listen to your body and do anything in slow steps. This can only hurt you if you overdo food versus need for fuel for your body.
- Watch out for tap water: fluorides and chloramines are toxins. Get reverse osmosis water. Do not get distilled water, it looks for electrons and will create free radicals in your body at a large rate.

Exercise more than you usually do: extended slow exercise works best, but the longer you can go the better. Do not kill yourself. Walk: if it means walking just around the outside of your house to start with—do it! Gradually build up the length and duration of your walk.

Watch what you touch: pumping gas, changing oil, fingernail polish and remover, all full of toxins. Wash your hands frequently!

Visit our website where we have [additional tips](#) to help you deal with your illness.



Recipe Corner

Awesome Fresh Low-Sodium Gazpacho



Cold soup can be welcome relief during these hot summer days, but typically gazpacho is loaded with salt with a whopping 740 calories in one cup if you use the canned, ready to serve kind! If you're trying to reduce the sodium in your diet, try this low-salt recipe.

Ingredients

- 3 medium tomatoes, peeled & chopped
- ½ cup cucumber, seeded & chopped
- ½ cup green pepper, chopped
- 2 green onions, sliced
- 2 cups low-sodium vegetable juice cocktail (V8)
- 1 tbs lemon juice
- ½ tsp basil, dried
- ¼ tsp hot pepper sauce
- 1 clove garlic, minced

Directions

1. In a large mixing bowl, combine all ingredients.
2. Cover and chill in the refrigerator for several hours.

Yield: 4 servings
Serving size: 1 1/4 cups
Recipe from [SparkPeople.com](#).

Nutrition Facts	
4 Servings	
Amount Per Serving	
Calories	44.8
Total Fat	0.2 g
Saturated	0.0 g
Polyunsaturated	0.1 g
Monounsaturated	0.0 g
Cholesterol	0.0 mg
Sodium	83.2 mg
Potassium	569.6 mg
Total Carbohydrate	9.8 g
Dietary Fiber	2.0 g
Sugars	5.1 g
Protein	1.8 g
Vitamin A	27.9 %
Vitamin B-12	0.0 %
Vitamin B-6	4.1 %
Vitamin C	97.5 %
Vitamin D	0.0 %
Vitamin E	1.3 %
Calcium	2.4 %
Copper	2.5 %
Folate	4.5 %
Iron	3.4 %
Magnesium	2.4 %
Manganese	4.1 %
Niacin	1.9 %
Pantothenic Acid	1.3 %
Phosphorus	1.8 %
Riboflavin	2.0 %
Selenium	0.4 %
Thiamin	2.7 %
Zinc	0.8 %

*Percent Daily Values are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.



Many thanks to Pandora.com for providing great tunes while composing both this newsletter and the articles contained herein!



Canada Day-July 2nd

Events this Month



July 14th



American Independence Day
July 4th



July 20th



Ramadan Begins

Trivia of the Month:

- Canada Day is the national day of Canada, a federal statutory holiday celebrating the anniversary of the July 1, 1867, enactment of the British North America Act, 1867 (today called the Constitution Act, 1867, in Canada), which united three colonies into a single country called Canada within the British Empire. Originally called Dominion Day the name was changed in 1982, the year the Canada Act was passed. This year because July 1st. falls on Sunday Canada Day is celebrated on the 2nd. Go Canada!
- US Independence Day celebrates the birthday of the United States of America. Founded July 4th 1776, with the signing of the Declaration of Independence, America is celebrating its 236th birthday this year (2012)!
- Bastille Day is the name given in English-speaking countries to the French National Day, which is celebrated on the 14th of July each year. In France, it is formally called La Fête Nationale . It commemorates the 1790 Fête de la Fédération, held on the first anniversary of the storming of the Bastille on 14 July 1789; the anniversary of the storming of the Bastille fortress-prison was seen as a symbol of the uprising of the modern nation, and of the reconciliation of all the French inside the constitutional monarchy which preceded the First Republic, during the French Revolution.
- Armstrong and Aldrin land on moon in 1969.
- Ramadan is a special month of the year for over one billion Muslims throughout the world. It is a time for inner reflection, devotion to God, and self-control. Muslims think of it as a kind of tune-up for their spiritual lives. There are as many meanings of Ramadan as there are Muslims. At Sundown. This date can vary by location.

Please let us know if there is a date that we should be commemorating or celebrating so we can add it to our calendar.



© None reported



Transplant Anniversaries

⚭ Dennis (dmanflan) July 9th

UNOS Waiting List Livers (June 22, 2012)

Status 1A	6
Status 1B	5
Status 7 (Inactive)	3,164
MELD / PELD <10	4,760
MELD / PELD 11-18	5,300
MELD / PELD 19-24	1,673
MELD / PELD 25+	1,249
Total Waiting	16,041

Courtesy OPTN reports

2012 So Far

1,553 liver transplants performed
1,712 livers donated/recovered



☞ "arod57" husband passed

☞ "kimmerz" husband passed