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by experts in the field of liver
disease

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HCV Treatment: Adherence to HCV Therapy

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ADHERENCE TO HCV THERAPY IS ONE OF THE MOST important predictors of successful HCV treatment. While there are well defined and established guidelines for other disease states such as HIV, hypertension and other diseases, it is less clear when it comes to adherence for HCV therapy. There is an established threshold of 80% for HIV, which means that if a patient does not take 80% of their medications, 80% of the time, the chance of a successful treatment outcome is greatly diminished. There have been retrospective (analyzing data from previous trials) studies on hepatitis C treatment adherence that have been able to establish the 80/80/80 rule. This means that someone taking hepatitis C medications is less likely to have a successful treatment outcome if they do not take 80% of interferon and 80% of ribavirin for 80% of the time. However, the 80/80/80 rule is controversial because it has not been studied in well designed prospective clinical trials. Another concern is that the 80/80/80 rule may be sending the wrong message about treatment adherence since it sets a lower threshold for taking medications rather than encouraging people to take 100% of the medications, 100% of the time or as close to 100% as possible – **especially** during the first twelve weeks of therapy.

Currently, pegylated interferon and ribavirin do not become HCV resistant so the question of adherence is only important right now with respect to treatment outcomes. However, questions of adherence will become even more important in the future with the development of anti-viral

therapies such as HCV protease and helicase inhibitors that will have the potential to mutate and become HCV resistant.

We do know that it is important to take as much of the prescribed medications as possible, but this can be difficult considering the moderate to severe physical and psychological side effects of HCV therapy. There are a number of predictors of treatment response to HCV therapy that are well-recognized as important and this fact sheet will discuss the importance of adherence and well-known strategies for helping people achieve a successful treatment outcome. It is also important to remember that not everyone will have a successful treatment outcome even with 100% adherence to HCV therapy.

Belief in Treatment

One of the most important predictors of successful treatment outcome is belief in the medications being used to treat hepatitis C. If a person believes that they will have a successful treatment outcome they will be more likely to take the important steps needed for successful treatment.

Building a Relationship with Medical Providers

Another important strategy is to build a strong and open-minded relationship with your medical provider; one which is nonjudgmental and non-threatening and which provides appropriate education. Medical providers should also encourage the use of support systems, and regularly evaluate psychosocial status as well as have a proactive approach to the management of treatment side effects. It is important that people develop a relationship with the entire medical team – not just with the doctor. In these times of managed health care, medical support staff may be actually managing your care more closely than your physician.

Customize Treatment Regime

It is important to customize the treatment regimen to meet the patient's lifestyle so as to make treatment part of, not all of, their lives. When feasible, people should be encouraged to continue working while they are on therapy, as work can help distract from the side effects and may increase their chances of staying on therapy. One specific strategy is to time the injections of pegylated interferon to coincide with potential side effects. For example, for

a person who works Monday through Friday, injecting the pegylated interferon on a Friday night will provide the weekend to rest up in case there are more side effects one or two days after the injection. Another strategy is to include pill organizers that can help keep track of when to take the ribavirin and any other medications.

Medical Providers' Experience

Another key component of adherence is managing the side effects of treatment before they become so severe that it would require a dose reduction or discontinuance of HCV medicines. There are several factors that will increase the likelihood of successfully managing treatment side effects, including the experience of the treating medical provider in managing side effects as well as the patient self-reporting the side effects in a timely manner. The HCV Advocate Web site has many side effect management fact sheets that provide a wealth of information about common strategies to help with side effect management. However, it is very important that the side effects are always managed by a medical provider – the final decision on how to treat side effects should always be made by the medical team.

Pharmaceutical Help

Pharmaceutical companies are another valuable resource. Roche, Schering and Valeant have web sites and toll free phone assistance available. The pharmaceutical Web sites can provide you with many tools, such as email reminders to take the medications or keep medical appointments, and personalized on-line journals to help track side effects and lab work. The pharmaceutical companies also have an on-call nurse that can help answer questions, provide phone support and even help with insurance reimbursement issues.

Keeping Appointments

It is very important that the person being treated keeps medical appointments and that blood work is routinely performed so that the medical provider can monitor any potential problems.

Social Support

Staying on treatment sometimes involves pulling together all the resources that are available. This includes as much support as possible from family, friends and employers. It

is highly recommended that a support system be put in place well before the start of therapy. One critical area of successful treatment adherence and outcome is attending a support group. Support groups are a valuable resource for helping with emotional issues that may come up while on therapy. There will be some members of the support group who have been on therapy and they can help with strategies on maintaining your health and managing side effects while on treatment.

Simple Tips:

- Make sure that you are mentally, physically and emotionally prepared to take on treatment so that you can give it all the attention and effort needed.
- Talk to your medical provider before starting treatment and discuss any potential side effects and strategies for managing any side effects that come up while on therapy.
- Try to plan ahead for any problems that may come up when on treatment that would prevent you from taking all of the medicines. For example, if you plan to travel while on therapy, make sure that you have the means to refrigerate the interferon and keep a copy of the prescriptions with you.
- Use a pill box to keep track of and remember to take ribavirin – try a seven day pill box available at most drug stores. A calendar will help to keep track of the interferon shots.
- Keep a side effect diary that you can take with you for medical appointments. Report persistent or bothersome side effects as soon as possible. Most of the side effects from treatment can be managed effectively if treated before they become severe.
- Don't forget to enlist the help of family and friends – you don't have to do this alone.
- Drink plenty of water or clear liquids without caffeine. If you don't like the taste of water, try adding a little bit of lemon or orange.
- Eat a healthy, balanced diet and try to maintain your weight.
- Try light to moderate exercise everyday if possible.

The Most Valuable Tool

The person with hepatitis C has the most valuable tool available –themselves – to help make treatment outcomes successful by being proactive in the management and treatment of HCV. This can be accomplished by using all the resources available to them, including family, peers, nurse, physicians assistants, nurse practitioners, case managers, pharmacists, psychologists and patient support programs.

The strategies discussed above can help give people a better chance for a successful treatment outcome. However, there are many other factors that influence treatment outcome such the type of treatment, HCV genotype, weight, HCV viral load, as well as age and race. It is important to remember that not everyone can achieve treatment success no mater how adherent they are to treatment. Although we should all strive for 100% adherence to HCV treatment medications, no one is perfect and there will be times when a person will forget to take a pill or may miss an injection by one day or so. There is nothing to be gained by playing the “blame game” because they are not 100% adherent – we are only human and perfection is an ideal not a reality. Remember to give it all you have; but try to be gentle with yourself especially while on treatment.

Resources:

Roche – Pegasys – Pegassist

<http://www.pegasys.com/resources/pegassist.asp>

Phone: 1-877-PEGASYS (1-877-734-2797)

Schering – Be in Charge

www.beincharge.com

Phone: 1-888-437-2608

Valeant – Infergen

www.valeant.com

Phone: 1-888-MOVE FWD (1-888-668-3393)

Hepatitis C Support Project – National Support Group listing

<http://www.hcvadvocate.org/community/groups.asp>

**Visit the HCV Advocate
Web Site:
www.hcvadvocate.org**

Below are just some of the publications and services you can find at www.hcvadvocate.org:

- HCV Advocate Monthly Newsletter (English)
- HCV Advocate Quarterly (Spanish)
- Educational materials in English, Spanish, French, Vietnamese, Russian, Tagalog and Chinese
- Medical Writers' Circle
- Hepatitis Journal Review
- Weekly News Review
- Disability & Benefits Column
- Hepatitis B information
- HIV/HCV Coinfection information
- Support Group Listings for USA, Canada and Elsewhere
- Links to Clinical Trials
- Links to other Helpful Organizations
- Event Listings
- Fact Sheet series: (English, French, Russian and Spanish)
 - *Easy C Facts
 - *Basics
 - *HCSP Fact Sheets

For more information about hepatitis C, hepatitis B and HCV coinfections, please visit www.hcvadvocate.org.

• *hcspFACTsheet* •

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