

LIVING POSITIVELY WITH HEPATITIS C



INTRODUCTION:

Brief overview on Hepatitis C:

The Hepatitis C virus was identified in 1989. It is a viral agent. It is associated with both acute and chronic liver disease. In many cases people infected with Hepatitis C virus may not become ill. However, some people develop jaundice. When liver inflammation persists for longer than 6 months the illness is called chronic Hepatitis C.

In my experience of working with clients over the years, symptoms tend to occur in cycles – you may have periods when you feel fine and then go through weeks when you feel absolutely exhausted.

COMMON SYMPTOMS:

(1) **FATIGUE:**

This is the most common symptom reported by persons with Hepatitis C. It ranges from mild to debilitating fatigue. It is important to state that the severity of fatigue is not related to the severity of the illness. The unpredictability of this symptom is particularly hard to cope with.

The temptation on days when you don't feel tired is to make up for lost time. Overdoing things and forcing yourself is not a good idea.

TIPS - HOW TO HELP YOURSELF:

- **Keep a record**: This will help you to understand what triggers a bout of exhaustion. It is a major tool in helping you help yourself
- **Rest**: The most important treatment is REST. Don't exert yourself to the point of exhaustion. On the other hand prolonged bed rest can lead to weakness and immobility. Keep a balance.
- **Sleep**: Try to restore a normal sleep pattern.
- **Develop an exercise routine**: This needs to be gentle. Don't push yourself beyond your energy limits.

(2) PAINS AND ACHES:

Many persons with Hepatitis C feel a variety of aches and pains. Chronic pain is itself a great stress.

TIPS - HOW TO HELP YOURSELF:

- Seek the appropriate medical advice.
- Exercise, carefully monitored can be helpful

• Don't feel guilty about your illness it was not your fault.

(3) LOSS OF SEX DRIVE:

Loss of libido is very commonly associated with Hepatitis C. Aches and pains, fatigue, depression and fear of transmission all contribute to a diminished sex life.

It is well documented in the literature that sexual transmission of Hepatitis C is RARE.

However, it is recommended that anyone who is sexually active should use condoms for all sexual contact. Having a disease that is sexually transmitted will certainly alter your attitude toward making love. It makes it very difficult to respond freely in the sexual aspect of your relationship. Sexual needs however are a basic part of healthy living and should not be ignored.

- If your sexual intimacy has diminished since your were diagnosed with Hepatitis C you are not alone.
- There is a void at the centre of your life and you need to address it with your partner.

TIPS - HOW TO HELP YOURSELF:

- Somewhere along the line the intimate relationship between you and your partner got lost speak to your partner openly and honestly about your feelings.
- Get professional help.

(4) **DEPRESSION:**

Stressful life events like a diagnosis of Hepatitis C make life very difficult. Some people cope and find ways to get through the shock but others find it difficult to cope with and this can lead to a depression.

Depression should not be ignored as it can take a terrible toll on a person and everyone else in the family. It is important to talk to your children and explain how you feel and reassure them that you are not angry with them.

Don't think it's all in your head and you can 'jolly' yourself along. Get help. With the appropriate medication and therapy things can improve significantly.

The cornerstone symptoms of depression are as follows:-

- **Loss of interest** in things you previously enjoyed.
- Mood Do you feel sad, hopeless and helpless – are you prone to bouts of crying?

- **Sleep problems** Do you have a disturbed sleep pattern? Do you often wake up at night or are you prone to early morning wakenings? Do you have difficulty falling back to sleep?
- **Appetite** Is your appetite significantly reduced or increased?
- Slow personal tempo Do you find everything on effort? Do you feel you are moving in slow motion? On the other hand are you agitated and irritable?
- Low self esteem Do you feel worthless and guilty?
- **Death** Do you have thoughts of death or suicide?
- **Concentration** Do you suffer concentration and memory problems?
- **Lack of libido** Have you lost interest in sex?

Finding out you have Hepatitis C changes your life. We recognise that persons needs vary greatly. Information and education are vital to help you understand the illness and improve your quality of life. Counselling services are now well established for persons with Hepatitis C. Counsellors can provide both practical and emotional support.

TIPS - HOW TO HELP YOURSELF:

- Find a good therapist to speak to.
 Therapy is more than just talking about depression; it is a way to help people understand its causes, its effects and its management.
- Avoid spending time with people when they are being negative and complaining.
- Learn ways to pamper yourself.
- Go to support meetings.
- Anti depressant medication can be very important in bringing relief from depression. Anti depressants do not have to be long term or addictive.

TREATMENTS FOR HEPATITIS C:

The aim of treatment is to eliminate the virus. Combination treatment using Interferon and Ribavirin taken together give best results.

Side effects are common and can be quite marked and distressing. It is important therefore that you understand why treatment is prescribed, what the possible side effects might be and how best to prepare for them.

HOW TO GET THE BEST FROM YOUR DOCTOR'S VISIT:

- Always prepare a list of questions you want to discuss.
- Take a relative or friend with you as this may make you feel more comfortable.
- Listen to what your doctor says. If you don't understand do not be afraid to ask again.
- Write down the important points.
- Check your list at the end of the consultation to make sure you have covered all the points.
- Don't be afraid to say how you really feel.
- Remember there are other people such as counsellors available to help, who may have more time to talk through particular worries.

Remember you are very much part of the team, the more involved you are in decisions of treatment the better you will cope. It is important to build and keep a good relationship with the Hepatology Nurse and Unit.

STEPS TO BEING POSITIVE ABOUT HEPATITIS C:

1. GET YOUR HISTORY STRAIGHT:

It is helpful to get your own medical history straight. Understanding medical terms and test results can be confusing. Don't be afraid to ask questions. The more you understand your condition the more you will feel in control.

2. RESPECT YOUR EMOTIONS:

It is not easy living with Hepatitis C with its uncertain prognosis. Chronic anger, sadness and fear drain our energy. We need to find appropriate outlets for these feelings. Speak to your therapist who is trained to help with these problems.

3. <u>LEARN TO LISTEN TO YOUR</u> <u>BODY:</u>

Pay attention when you feel tired. Don't push yourself through the tiredness. Rest as often as you need without feeling guilty.

4. GET HELP:

The psychological dimension of coping with Hepatitis C is now well recognised. Set aside time to talk to a skilled counsellor. These sessions will help you take stock and focus on your needs. You will learn how to talk openly and honestly instead of storing up your worries.

5. GATHER INFORMATION:

Significant progress in the understanding and treatments of Hepatitis C has been made over the years. Keep yourself informed of developments. It will help you feel hopeful and in control.

6. STAY INVOLVED IN YOUR LIFE:

Don't let Hepatitis C define who you are. Don't let it engulf your life. Learn to relax. There are many good books, tapes and courses available. Pace yourself. Don't overdo things. Avail of the support services. Also involve your family and friends. Don't be afraid to ask for help.

USEFUL ADDRESSES

1. Support groups

Positive Action

56, Fitzwilliam Square

Dublin 2.

Tel: (01) 676 2853 Fax: (01) 662 0009

E-mail: posact@indigo.ie

Positive Action provides information and support to women who have Hepatitis C from infected Anti-D products administered in Ireland, and to their families.

Transfusion Positive

3 Clanwilliam Square

Dublin 2

Tel: (01) 639 8854 / 55

Fax: (01) 639 8856

E-mail: transfusionpositive@eircom.net

Transfusion Positive provides information and support to people who have Hepatitis C from a blood transfusion in Ireland, and to their families.

Irish Haemophilia Society

Block C

Iceland House

Arran Court

Arran Quay,

Dublin 7.

Tel: (01) 872 4466 Fax. (01) 872 4494

E-mail: haemophiliasociety@eircom.net Website: www.haemophilia-society.ie

The Irish Haemophilia society provides information and support and services to all

people with bleeding disorders who have Hepatitis C, and to their families.

Irish Kidney Association

Donor House Block 43A Park West Dublin 12

Tel: (01) 668 9788 Fax: (01) 668 3820 Lo-call: 1890 45 65 56 E-mail: info@ika.ie

Website: www.ika.ie

The Irish Kidney Association provides information and support to people with kidney problems, including people who have Hepatitis C through dialysis or organ transplant, and to their families.

USEFUL ADDRESSES

2. Specialist Centres

St. Vincent's University Hospital

Liver Unit, Elm Park,

Dublin 4

Tel: (01) 209 4248 / (01) 269 4533

Fax: (01) 283 7724

Website: www.st-vincents.ie

Beaumont Hospital

Hepatology Unit, Beaumont Road, Dublin 9.

Tel: (01) 809 2220 / (01) 809 3000

Fax: (01) 809 2219

Website: www.beaumont.ie

Mater Misericordiae Hospital

Centre for Liver Disease, 55 Eccles Street, Dublin 7.

Tel: (01) 803 2048 / (01) 803 2000

Fax: (01) 803 4058 Website: www.mater.ie

St. James's Hospital

Hepatology Unit, James's Street, Dublin 8.

Tel: (01) 410 3417 / (01) 410 3000

Fax: (01) 410 3418

Website: www.stjames.ie

Our Lady's Hospital for Sick Children

Hepatology Unit, Crumlin, Dublin 12.

Tel: (01) 409 6571 / (01) 409 6100

Fax: (01) 456 3033 Website: www.olhsc.ie

Cork University Hospital

Hepatology Unit, Wilton, Cork.

Tel: (021) 492 2274 / (021) 454 6400

Fax: (021) 493 6383

University College Hospital

Hepatology Unit,

Galway.

Tel: (091) 544370 / (091) 524222

Fax: (091) 520233

St. Luke's Hospital

Hepatology Unit,

Kilkenny.

Tel: (056) 7752310 / 7785329 / 7785000

Fax: (056) 7752232

USEFUL ADDRESSES

3. Other Addresses

Hepcats

Tel: 087 791 7742

E-mail: hepcats_dublin@hotmail.com Hepcats is a self-help group set up by and for people living with Hepatitis C.

If you have a problem with drugs contact:

Merchant's Quay Project

Merchant's Quay

Dublin 2

Tel: (01) 679 0044 Fax: (01) 671 3738

Drug Treatment Centre Board

Drug Addiction Treatment Centre Trinity Court 30 Pearse Street Dublin 2

Tel: (01) 6488600

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