

## Complementary and Alternative Therapies

I have used Complementary and Alternative Therapies over the last 15 years as and when I have felt I have needed them, and when I can afford them as a regular "top me up". These have included Aromatherapy, Reflexology, Indian Head Massage, Reiki, Psychic healing, and recently Yoga. It is difficult to quantify how these work or what impact they have had on my health, but I still keep going back and using them because I believe they are effective. These therapies have definitely made me feel more relaxed, have reduced my stress levels and have helped me have a good nights sleep waking refreshed and invigorated.

These benefits alone go a long way to helping with my psychological health as well as boosting the immune system. Adding to the list of benefits are pain relief, the sensation of being energised and I believe a couple of opportunistic infections that were controlled by the "unorthodox" treatments. I also think it is good not to be too dependant on orthodox medication and treatment as the only option open to us. Complementary and Alternative Therapies are now being recognised and more accepted by the general population and some medical professionals. One would assume that this means they are more available but accessing and affording a therapist to help with our problems is not always easy. Most therapies cost at least £20 per session and home visits with other costs, such as oils, only add to this. Some areas do offer free or subsidised therapies for people living with HIV but across the board these are in decline.

Accessing research information to try and quantify why a certain therapy would be good for your individual condition can also be a difficult task for many reasons. Research trials are seldom carried out on complementary and alternative therapies and when they are the tools that are used to measure are often inappropriate. To complicate the issue, every therapy is different and has different effects. Every person reacts

differently to each therapy and most therapists have their own unique touch. So finding the therapy that works for you and a therapist that gives you the most benefit may take some experimentation and a bit of patience. Personal recommendations are always the best avenue in seeking a therapist and there are also numerous organisations that can put you in touch with a therapist of your choice in your area.

When using therapies for the first time it may be important to be prepared and ask the right questions. What should you expect, what results or side effects should you be aware of, how do you ensure there are no interactions with HIV medication, what are the dangers if any, how long should a course of treatments last, is the therapist qualified for example.

In this issue we have tried to give an overview of a number of the most popular Complementary and Alternative therapies, personal accounts from therapists who have worked with people in our situation combined with research articles and some useful contacts.

Whether you are a novice to these therapies or experienced, whether you use these as a complement to your HIV medication or as an alternative, we hope you find this issue of interest.

Paul

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# testing times for holistic therapies....

testing times....

Accessing information regarding research into the effectiveness of complementary therapies is not an easy task. Finding a research paper that says in "black and white" that a given therapy works or is beneficial to a particular condition would give weight and support to us accessing complimentary therapies, so why is it so hard to find any.

## Measuring the Immeasurable

Most research that has been conducted in the field of Complementary Therapies (CT's) has been subject to a fair amount of criticism- some warranted and some not. Most of the criticism is related to opinion as CT's are still considered the "new kid on the block" in terms of health treatments (even though most have been around and practiced for centuries). However many of the papers that have been criticised have been for the manner in which the research has been carried out and not necessarily the therapies themselves.

A lot of research has been frowned upon because:

- The studies have used only a small number of subjects.
- The data collected was largely anecdotal (e.g. client questionnaires were used to establish effectiveness, whereas a medical trial would involve blood tests)
- An appropriate placebo could not be found or used.

This would suggest that one of the major problems to date is that researchers have been trying to use the same tools to measure efficacy of CT's that Doctors have been using to measure the effectiveness of orthodox treatments and medical interventions. If we are going to make any progress into research for CT's we need to use new measuring tools and the methodology has to be improved, or alternatively anecdotal evidence needs to be universally accepted as "physical" evidence is at present. This issue of trying to fit a square peg into a round hole also brings up the question why we are trying to make CT's meet some kind of medical criteria in the first place.

CT's such as massage, reflexology and shiatsu all have numerous health benefits, but they cannot cure in the same way as conventional medicine, and individuals will respond very differently to the same CT's. Yet so much of the research carried out to date has measured them as if they can. Furthermore, it is extremely difficult to isolate which elements of a treatment are the effective ones. For example in aromatherapy, is it the actual massage, the smell, the aspect of touch, the absorption of oils or just the fact that someone has taken the time to listen to the client.

## Money matters

There could be studies that could look at the effectiveness of certain essential oils for instance as these could focus on the physical changes that occur within the body once the oils are inhaled or have been applied to the skin. These kinds of trials are expensive to conduct and there is a lack of funding into research into CT's. Any money that the government does afford to this area usually gets absorbed by Alternative Therapies (such as acupuncture and homeopathy) rather than Complementary Therapies. There may be other reasons why funds are not allocated to CT's so what would be an alternative. Independent funding of trials might work but who would trust a trial result into the efficacy of lavender oil if an aromatherapy oil manufacturer funded the study.

## The Glass is Half Full

Don't be disheartened if you cannot find the research into a particular therapy for your condition as the key point is to take on board the issues raised and consider these when researching in the future. There are many references on the Internet and medical journals in the library. If you don't know where to begin a recommended read is "Complementary Therapies: Is there an evidence base?" by Fiona Mantle (available from [www.nursingtimes.net/shop](http://www.nursingtimes.net/shop)).

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# holistic therapy...

My name is Angela and I trained as a holistic therapist five years ago and I now also teach therapies to small groups in community centres.

If you are wondering, 'What on earth is a holistic therapist?' I practice Aromatherapy, Reflexology, Indian Head Massage, Lymphatic Drainage and Reiki healing and am also trained in nutrition, first aid and counselling.

A holistic approach deals with the person as whole and great deal of time is spent with a client discussing their health background before deciding which, if any, treatment is most appropriate.

My reasoning for becoming a therapist was to help me find natural alternatives in dealing with the difficulties encountered over the years as a mother with a haemophilic son as well as the rest of my family. My son has severe haemophilia and also has HIV. Throughout my training as a therapist all of my family, in particular my son, were used as guinea pigs to fulfill the requirements for case studies.

Each client is given a thorough consultation prior to starting any treatment. All the therapies below are generally suitable for people with Haemophilia and / or HIV / Hepatitis C.

Reflexology takes the form of a specialised foot massage. It's a very helpful treatment for deep relaxation and is excellent for boosting the immune system through its natural detoxification processes.

Aromatherapy is a wonderful treatment, using specifically blended oils for whatever condition arises, helping cope with stress and promoting relaxation. I have also discovered an old remedy called Arnica oil, which is available as a massage oil or in a Homeopathic remedy which is excellent for soothing arthritic joints as it contains natural analgesic and anti-inflammatory properties.

Indian Head Massage is a great starter treatment. The head, neck, shoulders and upper back of a client are massaged to relieve stress or tension. IHM is particularly effective at helping insomnia and sinusitis.

Lymphatic Drainage is a specialised type of treatment not unlike massage. It helps to clear the body's lymphatic system of toxins by directly manipulating the lymphatic pathways. A course of this treatment is ideally given for 10 consecutive days. Although the benefits of this treatment are difficult to quantify, I feel that this may have contributed to my son spontaneously clearing the Hepatitis C virus.

In addition to the more common alternative therapies I am also a Reiki master. Reiki literally means "universal life energy", the power, which lives and acts in all created matter. The treatment consists of "laying-on" of hands in a structured way that releases the body's own energy channels or Chakras. The outcome of the treatment will depend on a client's needs.

Over the years my son has had lots of bleeds but it seems that his ankles have suffered the most and he had a synovectomy on one while he was studying for his degree. His other ankle, he has been told, has deteriorated too much to have the same treatment and the only surgery left on offer is to fuse the ankle. As a result the alternative therapies have become much more prominent in his treatment.

Although factor 8 is the first line of action for a bleed we have found using alternative therapies helps to reduce pain and promotes a general feeling of well-being in addition to speeding up the healing process. Despite all his problems my son succeeded in gaining a degree in social sciences and now holds down a full-time job with a large insurance company. I find my work as a therapist very rewarding and feel that I have helped my son in some small way to get through the many problems he has encountered over the years.

I was approached by the MacFarlane Trust about two years ago to provide therapies at a weekend in Liverpool for both people affected by Haemophilia / Hep C / HIV and their partners. I found the weekend very interesting. I enjoyed meeting other people in a similar situation to myself. In turn they felt more relaxed with me as a therapist because I could empathise with their problems.

If you have been on one of the weekends run by the Birchgrove, the Haemophilia Society or the MFT I may have already treated you. I attended the weekend in Coventry and at Manchester's Young People's weekend. I may see you at future events.

**ANGELA GODFREY (MICH)**

What on earth is a holistic therapist?

# homeopathy

I've been a homeopath for 8 years and treated thousands of people with hundreds of different remedies. Homeopathy can be safely used to treat anyone. I've treated pregnant women, newborn babies, children, men and women.

It can help people with acute illness, those living with long-term illness, even those in the final stages of life. It can help people with haemophilia, people with HIV, people with HCV and those with all three. It won't cure you but it can help to make you stronger both physically and emotionally, more able to deal with your conditions and more able to deal with the treatments you receive for them. I've seen it work – not least with my very own co-infected haemophiliac!

One of the principles of homeopathy is that we treat the whole person. This means looking at the mental, emotional and physical symptoms together and finding the remedy that best suits the individual. This is called constitutional homeopathy.

This is opposite to the approach taken by most practitioners of conventional medicine i.e. doctors. They treat the symptoms of the disease; everyone with the same disease gets a prescription from a limited range of drugs.

This difference has important implications for the way a homeopath works with a patient. So, what actually happens when you come for a homeopathic consultation?

An initial consultation can last up to two hours (very different to the average doctors appointment!). Most people come with a specific health problem in mind but the session will not exclusively focus on that. Seeing a homeopath is a good opportunity to talk about how you feel you are coping with life. The homeopath will give you plenty of time to talk about whatever is on your mind. Don't be put off if the homeopath has never treated anyone with haemophilia, HIV or Hep C. We are trained to treat the person not the disease!

make you feel better or worse. I'm sure you will have noticed that different people have different types of bleeds (even with similar factor levels), some people have more drug side effects whereas others seem to cope well. Not everybody reacts the same way to the same condition.

Your homeopath will also want to find out information about the kind of things that make us individual. The food we like or dislike, sleeping position, most comfortable temperature, best time of day, the best time of the year.

After the "physicals" we move on to your mental and emotional health. What is your outlook on life? Are there anxieties, worries and fears? If so, do you talk to someone about them or keep them inside? If you are feeling low is there anything that can make you feel better? How do you relax? What makes you laugh or cry? How do you react to certain situations e.g. being kept waiting, the house being untidy? What is your approach to taking your medication, are you always on time or it is a bit haphazard? There is no right or wrong answer; it's all about building up a picture of you and your life.

There will also be an opportunity to talk about significant life events. Homeopathic remedies can help us deal with any unresolved issues from the past as well as helping to maintain the best possible health in the present.

At the end of the initial consultation, which may have included laughter and tears, people are often amazed at how easy they found it to talk about themselves for so long. A good consultation can leave you feeling uplifted and unburdened (and that's before taking the remedy!).

So, you've survived the consultation, next comes the pills! (Known to homeopaths as remedies). I know for most of you the thought of taking any more pills will not fill you with joy. However, the homeopathic approach to prescribing means you may only need to take two or three tablets a month. The idea is that you give the minimum amount of the remedy and let the body use its own self-regulation to improve health.

what is it?

# SOHOMETHINGS

Many people find it difficult to imagine how such a small amount of the remedy can have any impact, especially if they are already on a daily drug regime. However experience has shown me that homeopathic remedies can and do work alongside heavy-duty conventional drugs (including antiretrovirals and interferon). There is no question of needing to stop conventional drugs for homeopathy to work and the remedies do not cause the kinds of interaction with your drugs that can result from other complementary treatments.

Homeopathic remedies come from many sources, which are often quite exotic. There are several thousand, made from a staggering array of substances. Remedies are made from minerals, plants, metals, precious gems, poisons, animal poisons and foods. And yes we do prescribe snake venom, arsenic, cannabis and opium!

After the initial consultation and the prescribing of the remedy there is usually a month until the next appointment (which will be shorter than the first). This gives time for the action of the remedy to become clear.

Having homeopathic treatment doesn't mean that there will never be another bleed or that your body will free itself from viruses. The aim of constitutional homeopathic treatment is to strengthen the body and help you cope better with life. Ultimately there should be a sense a feeling better in your self, of life flowing easier and continued personal development. At the same time you can receive treatment for minor ailments, specific symptoms or drug side effects as they occur and your homeopath will help you to learn to self medicate for problems you regularly experience.

So do I treat my own co-infected haemophiliac? No way! We each have our own homeopath which, keeps it ethical, and keeps us together.

If this article has got you thinking about homeopathy then look in the Yellow Pages under "Homeopathy" and you will find a list of qualified practitioners. They will have RSHom after their name.

Check out the Society of Homeopaths at <http://www.homeopathy-soh.org/>

**Diane Murray RSHom**  
Registered Homeopath

## Aromatherapy

Herbal oils have been used for centuries in many cultures to treat illness and promote well-being and beauty. The main principle of Aromatherapy is to surround the body with fragrances that make you feel comfortable, relaxed and at peace with yourself. The fragrances themselves come from the concentrated essences of plants which are individually blended by qualified practitioners and applied through techniques such as massage and vapourisation.

## Acupressure

Described as acupuncture without needles, acupressure probably predates its better known sister therapy. Part of Traditional Chinese Medicine, it is based on the theory of 'qi' or 'life energy' flowing through channels in the body known as meridians. Finger and thumb pressure is applied to acupoints to relieve ailments and promote harmony and health.

## Acupuncture

Acupuncture involves the insertion of very fine needles into specific points on the body. The origins of acupuncture are unknown but it has been practised for at least 5000 years in the Far East. Acupuncture needles are inserted into very specific points of the body which in turn unblocks the body's energy meridians, allowing Qi (life force) to flow freely.

## Aura Readings

The Aura, a field of energy that surrounds every living thing, is a reflection of the body's spirit energy. Kirlian Photography (pronounced kee-lee-an) measures the electromagnetic energy field. The brilliant colors presented correspond to the the energy fields that are unique to each person at the moment the picture is taken. The Kirlian effect is useful for recording energy balances and harmonies in all forms of life.

# Herbal Therapy in Patients with HIV

This article is based on a Conference report from the American Society of Health-System Pharmacists-Summer meeting 2002. The report notes that there has been increased use of Complementary and Alternative Medicines (CAM) over the past decade and especially within HIV diagnosed patients. The report describes CAM as unconventional, non-conventional, unorthodox, unproven or irregular medicines or healthcare. These derogatory terms do not help in the wider context of them being perceived as accepted medicines. Complementary medicine is one, which is used in conjunction with conventional medicines, and Alternative is used in place of traditional medical therapy.

## Patients using CAM

A survey conducted by Duggan and colleagues looked at 191 HIV+ patients of whom 67% reported using CAM's. In the group using CAM's 50% indicated they used herbal therapies as complementary therapy, with only 7% using CAM as an alternative to HIV medication. The paper did not state whether this 7% actually had a choice or whether they were treatment resistant. 64% of these patients stated that their doctors were aware of their use of Complementary therapies, with very few Doctors advising discontinuation of these products.

Between 1995-1997, the Alternative Medicine Care Outcomes in Aids (AMCOA) study looked at 1675 HIV+ men and women who used CAM's. Of this study group 63% were already using antiretroviral drug therapy. Participants reported the use of 1600 different types of CAM therapies, which included 1200 substances such as antioxidants, vitamins and herbs. The most common of these being Garlic, Ginseng, Echinacea Purpurea and Aloe. The participants indicated that CAM therapies improved their quality of life, reduced their stress and created a physical/spiritual balance. The purpose for which the patients used these CAM's were mainly to combat weight loss, control nausea and diarrhea, to fight HIV or boost immunity and to relieve stress or depression.

## Herbal Products and Safety

The potential benefits of herbal therapy in the report stated that these were relief of symptoms, increased sense of hope and empowerment and increased sense of control with health matters. However there are potential risks including interactions with HIV medication, mis-identification and labeling of herbal products that may not actually reflect their contents. Herbal products do not have to meet the strict quality controls that conventional medicine has to endure, as they are not considered medicines. The other item of note from this report is that some patients might delay conventional medicine treatment as they have a false sense of security with their natural products. Herbal products are often promoted as natural and therefore harmless, but several herbal products can contain ingredients that are carcinogenic or hepatotoxic.

## Herb-Antiretroviral Interactions

Interactions between HAART and Herbal medicines should raise concerns as some interactions may increase the toxicity of the Herb or the HIV drugs. Conversely they might also decrease the efficacy of both of these. For medication to work there must be the correct level of the drug in the body and some interactions might induce altered dissolution of drugs or bioavailability, altered absorption and altered drug metabolism and elimination. Some known interactions are ST Johns Wort with Protease inhibitors and NNRTI's, Garlic with Saquinavir and ritonavir and also theoretical concerns about the use of Echinacea Purpurea with HIV infection in general.

## Educating The Pharmacist

In the US a study of Pharmacists showed that 74% sold Herbal medications but only 45% had any education on herbal products, which underlined the need for pharmacists to become educated on their uses. The report concluded that Pharmacists and people in charge of your health care should be aware of the prevalence of herbal medications and the issues must be openly addressed and approached in a non-judgmental and matter of fact manner. The patient should be made aware of the benefits, risks and the contraindications of herbal therapy. Counseling a patient using herbal therapy should be no different than counseling that person for an over the counter prescription medication.

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# Herbal Medicine: What Are You On?

Aids Treatment Update, issue 110 of February 2002, produced an interesting article based on Herbal Medicines. This looks at the use of Herbal Medicines and their effectiveness. These looked at the, much talked about, Traditional Chinese Medicine, Side effects and safety issues and Herb-Drug interactions.

The key conclusions from this article are that Herbal medicines have some benefits in treating a wide range of health conditions, though there is no evidence they are useful in treating HIV infection.

Herbal medicines are associated with significant risks. They may cause both minor and serious side effects, and cause harmful interactions when taken with other medications. It is also advised that before you take herbal medicines, talk to your HIV doctor or pharmacists about possible interactions and side effects.

**Aids Treatment Update is published by NAM,  
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SW4 7AB**

## Kinesiology

Kinesiology is a diagnostic and therapeutic technique which tests muscle tone to discover what the body 'needs' to heal itself. Kinesiology assessment uses muscle testing to identify areas of stress and blocked energy. It is usually used in conjunction with Homeopathy, diet and nutrition supplements.

## Homeopathy

Homeopathy is a system of medicine which has been used around the world for the last 200 years. Each person is treated individually - a remedy is prescribed for the person as a whole, not just for their physical symptoms. In this way, homeopathy can be effective for a wide range of symptoms and conditions, Homeopathic remedies are made mainly from plants and minerals, and minute doses are used, which means that there are no toxic-side effects.

## Hypnotherapy

Hypnotherapy induces a trance-like state during which the person is so deeply relaxed that the unconscious becomes accessible to suggestion. Hypnotherapy can therefore be used either to reduce or eliminate symptoms, or in psychological treatment, enable patient and therapist to access material hidden from the consciousness. The goal of hypnosis is to help people gain control over behaviour, emotions, disease, addictions and habits. Hypnosis is commonly used to treat anxiety and conditions which have a strong psychological component such as addictions and irritable bowel syndrome.

## Indian Head Massage

Indian Head Massage combines a blend of traditional Indian Massage techniques and the Ayurvedic Healing System. The massage, which is received fully clothed and seated in a chair, concentrates on easing upper body tension. Massage techniques are applied to the head, neck, shoulders and upper back. The receiver benefits from improved circulation, joint mobility, muscle tone, relaxation and a feeling of peace and well being. Particular oils may be used to enhance the effect of the massage - this is optional.

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# no mean feet!

Having just returned from 'Something for the weekend' I feel relaxed and more at ease with myself. Partly due to the excellent company I kept but also because I was able to access a FREE Shiatsu session.

I am a complementary therapy practitioner myself and ironically cannot usually afford regular therapy sessions for myself. The support services for people affected by HIV are virtually non-existent in my area. There is a drop-in that my partner accesses and is able to receive subsidised therapies but this is not open to me as a partner.

In my work as a Reflexologist I was able to access funding for a client (H), who is HIV+ and resistant to HAART, from his local Primary Care Team

H wrote to his consultant explaining that he had tried Reflexology, felt the benefits from it and would like to continue but could not afford to. I wrote to the consultant outlining the benefits of Reflexology (being careful to emphasise the relaxation side of the treatment), gave him details of my background and experience and hey presto – the application for funding was accepted. The consultant stated..

**“..this series of treatments will integrate with the care H is receiving from (his hospital).”**

I received £30 per session to visit H in his home for an initial 6 weeks, which was to be reviewed.

H's general well being improved during those 6 weeks – his high Viral Load reduced by a third and a number of opportunistic infections, which had been present before the treatments, improved dramatically. H

reported on a more personal level that he had benefited from:-

**“psychological uplift, relaxation and time for myself and a better nights sleep following treatment”**

The consultant agreed to continue to fund fortnightly treatments stating

“I note that H is making progress and is feeling more relaxed and energetic as a result of your treatment.”

Recognition at last! I continued to see H for a year – his health continued to improve and he looked forward to his fortnightly sessions.

I no longer see H due to personal circumstances but he has made contact with another Reflexologist and his sessions continue to be funded by the PCT.

I did receive a rather disturbing phone call from this practitioner, however, asking me if she should wear rubber gloves whilst treating H!! After I pointed out that if she followed her code of practice, i.e. any open sores on any client or indeed on herself should be covered up to prevent cross infection, H should be treated no differently from anyone else! There's still a lot of ignorance out there isn't there?!

So in this case a little bit of teamwork went a long way – perhaps practitioners and HIV+ clients could try this 2 line approach and see what happens.

To find a practitioner in your area check out The Federation of Holistic Therapists at [www.fht.org.uk](http://www.fht.org.uk) Tel: 023 8048 8900

**Pip Higgins** RMN; MBSR; MIGHT

“psychological  
uplift, relaxation  
and time for  
myself and a  
better nights  
sleep following  
treatment”



# Directory Of Complementary Therapies in HIV & aids

The Directory of Complementary Therapies in HIV and AIDS is a comprehensive guide to the use of complementary therapies by people living with HIV and AIDS. Published by NAM and edited by Anna Poppa this book was printed in March 2002 and gives a good insight into the various complementary therapies available and how they interact with HIV. Topics covered are how and why people use complementary therapies; choosing and using therapies; problems to consider; and making the right choices. It lists what questions to ask a practitioner and how to understand the information about effectiveness as well as combining conventional and complementary therapies. There is a comprehensive guide to complementary therapies in an A-Z format; descriptions of each therapy; what to expect from them and where research evidence exists.

It also gives key contacts for the affiliated professional bodies and organisations that can put you in touch with therapists in your area.

## Massage

Massage is one of the oldest and simplest forms of complementary medicine and perhaps one of the most widely used today. Swedish massage tends to be the basis of most approaches to massage. It involves a number of manual techniques aimed to relax, strengthen and stimulate the muscles. Holistic massage is a term used for massage that addresses the whole person - most masseurs use this approach. Massage is applied to the muscles and ligaments, with the aim of relaxing the nervous system, improving circulation, stimulating the flow of oxygen-bearing red blood cells around the body and assisting the elimination of toxins.

## Reiki

A form of Japanese spiritual healing, the word Reiki is derived from rei (universal) and ki (life energy). It has its foundations in ancient Tibetan Buddhism. Practitioners draw on 'reiki energy', channelling it to areas of need in themselves and their patients to rebalance and replenish areas where needed. A reiki session involves laying on of hands and leaves the receiver feeling relaxed and calm.

## Hopi Ear Candles

Thermo Auricular Therapy (also known as Hopi Ear Candles) is a pleasant and non-invasive treatment of the ears, used to treat a variety of conditions. This is an ancient and natural therapy handed down by many civilisations. It is believed that the Ancient Greeks used ear candles, initially probably for cleansing, purifying and healing on a spiritual basis, but much later on a purely physical basis. However, the practice reached the modern world via the native American Hopi Indians of North Arizona.

The candles are made from the natural ingredients of beeswax, honey extracts, sage, St Johns Wort, chamomile, beta-carotene and organically grown flax. A constant high quality is ensured. The candles work on a chimney principle, drawing any impurities to the surface where they can be gently removed. They equalise the pressure in the head and ears, making them suitable for most conditions. Secretion flow is gently stimulated and the vapour collects and removes impurities or deposits.

Most of these are carried away through the candle "chimney", although some of them can be found in the condensed candle wax residue after removal from the ear, or could even work their way up to the surface 24-48 hours after. You are asked to lie comfortably and listen to relaxing music. The candle is then gently placed into the auditory canal, where it is lit and held in a vertical position, keeping the candle steady and preventing any ash falling on to you. You will experience a pleasant crackling sound as the candle burns and a warm comfortable feeling. As the candle burns down, the residue ash (if it falls) will just turn to dust.

The candle is then taken away while you lie there for a few moments before turning over to treat the other ear. Most clients find the whole experience very relaxing. Some fall asleep during treatment.

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# Dear Diary...

Dear Diary

This has actually not been so bad. Mondays and Tuesdays are bad but the rest of the week okay. The diarrhea and constipation seemed to have gone away as has my weight. It is noticeable in my face. Anna has suggested it may be because I am not drinking beer any more and that that kind of makes sense - there are lots of calories in beer you know!

**Week 6:** get my essay in and although a bit of a slog, the interferon at least made me start it early. I am chuffed to bits with finishing it. A cup of tea does not quite feel like the way to celebrate though, and joining other course members for a lime and soda whilst they hit the beer is just a little bit rubbish.

**Week 7:** I have some bad nights sleeping. I get about 3 hours in bursts of 1 or 2 hours and then am shattered all day. A new interferon side effect - whoop, whoop! Coincidentally am seeing my HIV doctor and after describing it to him - a difficulty in relaxing and calming down to sleep, and inability to fall back to sleep; he suggests 'Zopiclone' which has worked well for people taking an HIV drug. It helps! I check with a friend who works with drug users about addiction or withdrawal and she confirms the rule that the effect usually only lasts for 3 months and although not addictive, has been used recreationally and probably has a withdrawal. I decide to take it for half the week. Apart from a bad night on Thursdays this works quite well.

**Week 10 and a holiday.** Double figures reached and it has not been so bad. This is just what I need, an International Conference (Portugal in a heat wave). It is beautiful, one particular evening I sit on my hotel balcony and

listen to music on my Walkman in the hot (yes, HOT!) sun. The conference is almost perfect, a meeting with old friends, new interesting people, a great restaurant meal paid for by a drug company rep and a long flirtatious evening with a nurse. (Oh and they liked my workshop too.) I return refreshed and feeling immensely confident for the rest of the year.

**Week 12:** It does not last more than 3 days when I next see the doctor. The third of my monthly appointments at St Thomas and a special occasion I see Babu rather than the Haemophilia registrar. Babu notices my weight loss and feels it is probably due to an interaction between the ribavirin and Stavudine. My cheeks have are like me mood, flat and dents appear on the inside of my elbows. It is also painful to sit down. My bum seems to have disappeared and whilst I cannot really say it is my favourite feature I am quite attached to it. I never really

noticed how many hard seats there were in the world before. Babu says I should think about changing my HIV combination.

The changes are probably permanent and the only facial treatment is cosmetic and short-term. It has also not been tried in haemophiliacs and is not recommended by the makers. Does someone up there not like me or what? It

has come on really quickly though and is very noticeable to people who have not seen me for a couple of months. I am still taking the drugs that are working together to cause this and I have another six weeks until my next appt with my HIV doctor.

I find it really hard to swallow the damn tablets. I won't give up the hep c drugs. The pegylated interferon has a tiny anti-HIV effect so perhaps I could just stop the HIV medications until the end of the year on interferon. I miss the HIV drugs one morning as I just cannot take them. I do not feel I can go on taking them whilst I wait for that appointment. I speak to the HIV pharmacist at the ward where I am giving the next interferon injection and she says I should keep taking the HIV drugs and see someone soon.

After prevaricating with the worst of both worlds

## My Peg-Interferon/ Ribavirin Treatment Diary

Weeks 5-10

Does  
someone  
up there  
not like me  
or what?

# Dear Diary...

(continued)

taking tablets only once one day not the next then once on the third day (am I trying to make my HIV drug resistant or what?) I stop the HIV medicines altogether. I make an appointment to see a doctor, any doctor at my HIV clinic for the following week and go away for the weekend.

Come back to a message on my answer phone saying that Dr Fisher, my HIV doctor can see me at the ward as he is doing a ward round then. I ring, book it and feel relieved. I see him and say that I have stopped taking the HIV meds and he says that I have made a logical choice to eliminate the drug causing the problem. That makes me feel a bit better. I ask about not taking any more HIV meds until I have finished the Peg and Rib. He is less certain about that and says that his understanding was that the higher ones CD4 cells the greater the chance of a sustained viral response, the so-called 'cure'. We look at his recommendation of combinations and I make an appointment to see the pharmacist the next day to think about it.

It is going to involve a Protease Inhibitor with its risk of more or unusual bleeds. I read all the leaflets working out the easiest one to take with the least food restrictions to be ready for the pharmacist. Lo and behold the easiest one to take that fits in best with my life-style is the one Dr Fisher suggested. He is just a bit too good this doctor...

The pharmacist has checked the known interactions with ribavirin and I can take all my tablets at the same times. However, they must all must be eaten after food. This is not just to avoid feeling uncomfortable but to ensure a good level of each drug exists in the blood stream. You have to eat first in order to make the drugs work. I start that evening.

***Check out the next Issue of Birchgrove for the next installment of Robert James's thrilling treatment diary.***

## Reflexology

Foot massage has been practised for centuries. According to Reflexologists, the feet and hands are a mirror of the body, and pressure placed on specific reflex points on them can be used to treat the corresponding areas of the body, in order to stimulate natural health powers and promote well-being. All parts of the foot are massaged, so that the body as a whole is treated. The therapy has become popular around the world and is often used in conjunction with aromatherapy.

## Shiatsu

Shiatsu massage was developed in Japan early in the 20th Century. Although influenced by Western Medicine, it has its basis in Traditional Chinese Medicine and follows the same principles of energy and meridians as acupuncture. The practitioner uses fingers, thumbs, elbows, knees and even feet in a combination of massage techniques, applying pressure to key points to influence and stimulate energy flow in the body.

## T'ai Chi

T'ai Chi is practised by an estimated seventy million Chinese every day and is a form of exercise which uses slow and flowing movement to both discipline and calm the mind, body and spirit. The exercises are intended to centre and direct Qi, the life force. Like Yoga, T'ai chi is meditative exercise rather than a vigorous sport and it involves 108 movements that are performed in a specific order.

## Yoga

Best known in the West as a form a gentle exercise consisting of body postures and breathing techniques, yoga is in fact a complete system of mental and physical training, originally developed as preparation for spiritual development. It has been practised for thousands of years in India as part of Ayurveda, and has now become popular around the world. It is valued more for its physical than spiritual benefits, such as its ability to increase suppleness and vitality, and to relieve stress.

# CAMPAIGN NEWS

SUNDAY EXPRESS  
AUGUST 18, 2002

EXCLUSIVE BY LUCY JOHNSTON  
Health Editor

## Politicians may face criminal charges over infected blood.

FORMER Tory and Labour ministers could face criminal charges over the use of contaminated blood in the NHS which infected thousands with HIV and hepatitis C. The Association of Chief Police Officers is to examine evidence which reveals key health and Treasury officials across two decades ignored repeated warnings that blood products used in the UK were putting lives at risk. Terence Grange, chairman of ACPO's

personal crime division, has written to the Crown Prosecution Service to see if there is enough evidence for a criminal prosecution. Thousands of people received contaminated blood or blood products from the Seventies until the early Nineties. The scandal has been described as the worst medical treatment disaster in the NHS's history. So far up to 2,000 have died and another 4,000 infected or dying. Pregnant women and individuals undergoing operations were among those given infected blood. But most at risk were haemophiliacs who were repeatedly injected with unsafe imported blood-clotting products.

One victim was Colette Wintle, 43, from Tonbridge Wells, Kent, who was infected with hepatitis B and C in 1982 from blood products used to treat her haemophilia. The former nurse said: "I am in constant pain and often exhausted. I am terrified about my future. I have the most lethal and difficult-to-treat type of hepatitis C. Mr Grange's move follows the convictions of former health ministers in Italy, France and Japan. Last night he said: "This could well be a scandal. If the allegations in the documents are true we may have to involve criminal law." The new legal move comes as the Government orders hospitals to import US blood supplies to ensure children under six are not infected with CJD, the human form of mad cow disease.

Furious health campaigners say American blood has an appalling contamination record and point to recent evidence of US safety violations. Mr Grange will examine Government memos, internal blood company documents and secret reports from the Government's Public Health Service Laboratory which reveal UK health officials have long ignored warnings that blood products were dangerous. Some of these documents have been seen by the Sunday Express. One, dated May 1983, from the PHSL to the Health Department, advised immediate withdrawal of all US blood products because they had caused three HIV infections in haemophiliacs. They never were.

*Thousands of people received contaminated blood or blood products from the Seventies until the early Nineties*

### Trustees needed for Macfarlane Trust board

The Haemophilia Society and Macfarlane Trust are seeking to fill two vacancies on the MFT board. These arise following the retirement of trustees Ian Hayes and Pat Latimer at the end of the year. There are ten members of the Trust's board, four are appointed by the Department of Health and six are appointed by the Society. The new trustees will be among the six Haemophilia appointed places.

The Society and the Trust are keen to see these two vacancies filled by affected people and applications are welcome from people living with haemophilia and HIV, partners, carers and widows. A trustee job description is available from the Macfarlane Trust (020 7233 0057). Those interested will need to submit a written application to the Haemophilia Society indicating that they are able to meet the job description requirements by Friday October 25, 2002.

If you would like an informal discussion about what the role of trustee involves Ian would be happy to talk to you.

Email: [murrayhayes@cwcom.net](mailto:murrayhayes@cwcom.net)

ANOTHER is a letter from American hepatitis expert to the Government blood products Laboratory, dated July 1975. It warned US blood was taken high-risk groups such as prisoners and

*Those who were responsible here in Britain should be made to stand trial, too.*

“skid-row derelicts” and was “extraordinarily hazardous”. The letter stated the hepatitis

infection rate from this blood was up to 90 per cent. Another letter dated July 1981, from the Department of Health to a senior member of the Treasury expressed concern “because of the hepatitis risk”.

Carol Grayson from Haemophilia Action UK, said: “Successive Governments have not ensured blood products are safe. We have no option but to seek a criminal investigation. Peter Mossman, a campaigner and victim added: “We have met health ministers over the years but none have given us answers. We have no alternative.”

In the past there have been several moves to compensate victims but nobody has accepted liability. In 1987, former Labour health minister Lord Owen asked for an investigation but was told his files had been “pulped”.

A Department of Health spokeswoman said: “The technology to make blood products free from HIV and hepatitis C was not available until the mid-Eighties. As soon as it was we introduced it.”

## SUNDAY EXPRESS OPINION

Make those responsible for blood fiasco face justice. OUR revelation today that health officials ignored repeated warnings that blood products used in the UK were potentially lethal beggars belief. The figures are quite staggering: up to 2,000 people died as a direct result of being infected with contaminated blood or blood products and a further 4,000 are currently infected and in some cases, dying.

This tragedy was entirely avoidable: as early as 1975, US hepatitis expert Dr Garrett Allen warned the UK Government Blood Products Laboratory that US blood was “extraordinarily hazardous”. And this, mark you, before HIV and Aids had been properly identified. What more would anyone have to say to highlight the risks? As it happens more was said throughout the Eighties warnings continued to come through - and continued to be ignored. And so thousands

of patients were injected with contaminated blood: most notably haemophiliacs, who were repeatedly injected and, as a result, became infected with HIV and hepatitis C.

When, a couple of years ago, similar cases came to light in France, the reaction on this side of the channel was horror. It seemed inconceivable that officials charged with looking after public health should have knowingly allowed the sick and vulnerable to be infected with a potentially fatal disease. It couldn't happen here, we were assured. Safeguards were in place and, indeed, those poor unfortunates infected with HIV before the full scale of the problem became known were recompensed financially more than a decade ago.

But back then, no one had any idea that warnings had already been made and no amount of money, however generous, can compensate for living with a disease that will one day strike you down. Meanwhile, the patients infected with hepatitis C, quite as nasty a condition as being HIV positive, have received no compensation at all. This is a disgrace. In France, a former health minister was convicted for failing adequately to screen contaminated blood.

Those who were responsible here in Britain should be made to stand trial, too.

# Bob the bleeder...

*If you have a conundrum, a query or a problem please write in and Bob will try to fix it.*

**Dear Bob,**  
***I have never used any of these complementary or alternative therapies, do you have any recommendations?***

Yes, write to the Mac Trust for their complementary therapies taster grant of £200. You do not even have to wait long for it as it is sent out automatically to anyone that has not had it before. When I got mine I decided to try out aromatherapy. The thought of being rubbed in sweet smelling oils by some blonde just somehow appealed to me more than making a cup of tea with foul tasting herbs. So with the 200 quid in my pocket I decided to find a selection of suitable aromatherapists with the requisite experience and spiritual aura. I found a particularly wide selection of practitioners was available in my local phone box. There dozens of brightly coloured business cards for me to choose from and I took half-a dozen;

Busty Brunette, New in town, well built blonde, Sexy Sam, Foxy Lady and Busty-42DD. Speaking to them I discovered that Busty Brunette was not there but I could see a busty blonde called Ulrika who seemed to have a Geordie accent but offered everything for £50. New in town had left town but I could see Busty Brunette, Jade. I asked if she was the Busty Brunette available at the other number but she told me to sod off and hung up. Well built blonde's number was unobtainable and Sexy Sam surprised me with his deep voice. I apologised that I was not really looking for a man but he did offer free head if I was cute so I said okay. After all you can't look a gift horse in the mouth like that everyday.

Foxy lady sounded more foggy than foxy to me calling me John repeatedly, asking if I had any gear and slurring her words. Finally she stopped talking altogether and seemed to be snoring. I thought it best to leave her. Busty-42DD turned out to be my neighbour over the road and we had a grand time moaning about the rubbish not being collected by this new private company.

N.B. My friend Vic tells me that I have tried one other complementary therapy, that of Amaroli or urine therapy. Now drinking urine may be a sensible alternative when your trapped in the Australian desert for a few days and the only alternative is death or an Aussie lager that tastes like XXXX.

I also admit that after the odd boozy night out I may have been unable accurately recall the events of the previous evening, or my own name, but I feel certain I would remember literally taking the piss. I suggest he is confusing amaroli with amoretto liqueur which I have discovered doesn't work as a complementary therapy, even after a couple of bottles. Vic says no and that since being aware of the healing powers of urine he regularly pisses in my pint.

Finally some of you may have noticed that an obscure publication called HQ (daft name if you ask me) by a group describing themselves as "The UK Haemophilia Society" which has a picture of a man on the front cover with a very similar name advertising 'Jeans for Genes'. I would just like to take this opportunity to reiterate that he is no way related to me or this column but in a spirit of generosity I am prepared to join in this charity campaign. I am offering my nearly new but never used blood clotting genes for a pair of 501s. If interested e-mail me at birchgrove1@hotmail.com

*I found a particularly wide selection of practitioners was available in my local phone box!*

...can he **fix** it?

# Resources and Information about HIV and Hepatitis

## Information and support

### British Liver Trust

Information, advice, support and campaigning on all aspects of liver disease including viral hepatitis (A,B,C,etc). A variety of publications and web based details.

**Tel: 01473 276326**

Email: [info@britishlivertrust.org.uk](mailto:info@britishlivertrust.org.uk)

**Website: [www.britishlivertrust.org.uk](http://www.britishlivertrust.org.uk)**

### Haemophilia Society

Information, advice and support.  
HIV/HCV worker Babs Evans  
[babs@haemophilia.org.uk](mailto:babs@haemophilia.org.uk)  
Hepatitis worker John Morris  
[john@haemophilia.org.uk](mailto:john@haemophilia.org.uk)

**Tel: 0800 018 6068**

Email: [info@haemophilia.org.uk](mailto:info@haemophilia.org.uk)

**Website: [www.haemophilia.org.uk](http://www.haemophilia.org.uk)**

### HIV and Hepatitis.com

Online publication about treatment.

**Website: [www.hivandhepatitis.com](http://www.hivandhepatitis.com)**

### Mainliners

Support, advice and information for people affected by drugs, HIV and hepatitis.

**Tel: 020 7582 5434**

Email: [linersmain@aol.com](mailto:linersmain@aol.com)

**Website: <http://members.aol.com/linersmain>**

### National AIDS Manual

Provides up to date factual treatment information via free publications and website.

**Tel: 020 7627 3200**

Email: [info@nam.org.uk](mailto:info@nam.org.uk)

**Website: [www.aidsmap.com](http://www.aidsmap.com)**

### The National Hepatitis C Resource Centre

Information and advice for HCV+ people, professionals and the general public.

**Tel: 020 7735 7705**

Email: [advice&info@hep-ccentre.com](mailto:advice&info@hep-ccentre.com)

**Web site: [www.hep-ccentre.com](http://www.hep-ccentre.com)**

### Positively Women

Peer-support services to HIV positive women and their children. Drugs and alcohol support group and bi-monthly newsletter.

**Tel: 020 7713 0222**

Email: [info@positivelywomen.org.uk](mailto:info@positivelywomen.org.uk)

**[www.positivelywomen.org.uk](http://www.positivelywomen.org.uk)**

### Positive Nation

Monthly publication providing a platform for all people affected by HIV and AIDS in the UK.

**Tel: 020 7564 2121**

Email: [subscriptions@positivenation.co.uk](mailto:subscriptions@positivenation.co.uk)

**Website: [www.positivenation.co.uk](http://www.positivenation.co.uk)**

### +HEP

Monthly publication about HIV and quarterly issues about hepatitis

**Tel: 01895 637878**

Email: [andrewb@akitanet.co.uk](mailto:andrewb@akitanet.co.uk)

**Website: [www.howsthat.co.uk](http://www.howsthat.co.uk)**

## Booklets on hepatitis

### A rough guide to hepatitis

Pocket-sized booklet with information about all aspects of hepatitis (from A to G). Produced by How's That Publishing Limited

**Tel: 01895 637878**

### Hepatitis C...meeting the challenge

Aimed at adults living with a bleeding disorder and HCV or HIV and HCV co-infection. Produced by the Haemophilia Society.

**Tel: 0800 018 6068**

## National Helpline Numbers

### National AIDS Helpline

**Tel: 0800 567 123**

24 hour helpline offering advice on HIV/AIDS

### Terrence Higgins Trust

**Tel: 020 7242 1010**

days per week 12-10pm Advice on HIV/AIDS

### Positive Line

**Tel: 0800 1696806**

staffed by positive people mon-fri 11am-10pm  
sat/sun 4-10pm

### AIDS Treatment Phone line

**Tel: 0845 947 0047**

Treatment advice from positive people  
Mon + Wed 3pm-9pm Tues 3pm-6pm

### HIV i-Base

HIV treatment information and support.

**Tel: 0808 800 6013** (treatment info helpline)  
**020 7407 8488**

Email: [admin@i-Base.org.uk](mailto:admin@i-Base.org.uk)

**Website: [www.i-Base.org.uk](http://www.i-Base.org.uk)**

### Immune Development Trust

Offers a broad range of holistic therapies and advice to HIV+ people

**Tel: 020 7704 1555**

**Website: [www.idt.org.uk](http://www.idt.org.uk)**

## The Speaking Chair 4

Well I have just got back from 'Something for the weekend' and I found it a really good 'something'. It is so good to see people from way back when and know that they are well. Sadly I did not get to enjoy the weekend to the full as I could not cope with the usual level of alcohol and sleep deprivation but others seemed to make up for me.

Lots of past, present and hopefully future writers and editors of Birchgrove were there and as always we want others to write something for us. No experience necessary, ability would be great as long as it does not show how bad I am at it. Birchgrove was heavily involved in the planning and organisation, had a stand, sung karaoke in flat voices and asked for feedback. – Do you think the magazine is ok, rubbish or great. If you were there or not, answers on an e-mail please...

Birchgrove was also invited by Mainliners to the launch of a Hepatitis C awareness campaign at the House of Commons. Sadly it was in a new building across the road from Big Ben so no chance to look out from the chamber over the river at St Thomas' Hospital rather than the other way round. 'Wake up to Hep C' is aimed at the general public and health care professionals and you can download the poster at :

<http://www.isvad.com/hepccentre/hepcaware.htm>

Take it in to your haemophilia centre and see if anyone there has heard of the disease. (If they have not I suggest you start looking around for another centre). I thought I'd put it up at my HIV clinic as the consultant is an Arsenal fan. After that Birchgrove ran a workshop at the Aids and Prisons Forum Annual Conference on HIV/HCV Coinfection. This event was, as always, really interesting and demonstrated what a different world life in prison is, both for staff and inmates. Best thing I can say about it is that it might be okay to visit but you really would not want to live there!

### Robert the Chair

The next Issue will give feature a report on "Something For the Weekend"

## Birchgrove is a Forum for:

The treatment of haemophilia and HIV

Taking best care of ourselves, through informed debate.

Staying healthy with both haemophilia and HIV/AIDS

Ways in which HIV affects love and sexuality

The social and psychological aspects of haemophilia and HIV.

## We believe that people with Haemophilia and HIV...

Can be empowered and enabled to deal with HIV/AIDS through relevant information and mutual support.

Can improve their health and extend their lives by expressing feeling and confronting the issues directly

Should be heard and have their needs recognised and not suffer inn fear and isolation.

Have a role in the work of the HIV/AIDS community to inform and challenge the ignorance that exists about HIV.

Editorial Team

Mick Mason and Paul Bateman

## DISCLAIMER

The views expressed in each of the articles are those of the individual authors, and not necessarily those of Birchgrove.

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