Birchgrove

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SEX & CONCEPTION ISSUE

Living with HIV and making decisions about whether or how to have children brings up many different issues and feelings for people. From sperm-washing to fostering, to doing it naturally or not at all. Would you like to have children but are worried about transmitting HIV and/or HCV? Do you have concerns about the genetic risk of haemophilia? Did you think having children was impossible ? For many people in our situation the choice of having children has not been on offer. For many, having children naturally has been a choice or accident as they are in any one else's life who doesn't live with HIV.

There have been recent news reports of improved sperm washing and assisted conception techniques and improved choices for people in our situation, but what is the reality? Is this something you want to think about? Are you getting the right information? Are you getting the right support to make the right decisions for yourself? Is funding a problem?

When Birchgrove was approached to consider writing an issue on conception we knew it wouldn't be easy as the strength of feelings and emotions around this topic are so acute for some. A number of people contacted us stating that although they had experience they could share with others, it was just too emotional and personal to write something about it.

As many of us are facing a changing life expectancy due to improved medication we also have changing needs, and many people are now looking towards the future and considering having children and a family. We hope that through the articles, personal experiences, reports and information we have collated on Conception and related topics that this edition of Birchgrove will give an opportunity for readers to become more informed on this topic.

We hope that we have approached this issue sensitively enough and understand that for some this will be difficult reading material.

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contents...

reproductive

A report from a workshop held at "Something for the Weekend" 2002

by Mike O'Driscoll

The workshop commenced with an introductory talk by Lara Ovesiky, Haemophilia Nurse Specialist at the Haemophilia Centre, Churchill Hospital, Oxford.

Lara's presentation began with an overview of the implications of having or wanting to have children on HIV sero-discordant couples, where the haemophiliac man is affected with HIV while his partner is HIV negative. Before even considering the question of possible transmission of HIV, she stressed the importance or providing the couple with relevant information on the effects of haemophilia, it's inheritance, the possibilities of antenatal diagnosis, the consideration of selective abortion and the new reproductive opportunities, in order that an informed decision about proceeding with having a family can be made.

The main body of the presentation comprised an analysis of the latest statistics on the risk of transmission, with current estimates for unprotected vaginal intercourse, between an HIV+ man and a negative woman, carrying a 3-6 in a 1000 chance of transmission.

The risk of vertical transmission i.e. from HIV+ mother to child, is approx. 15-20%, with this risk increasing if the mother goes on to breast-fed. This may be reduced by 50% if the mother is treated with anti viral drugs during pregnancy, at delivery and to the baby once born, and may be halved again if the mother opts for Caesarean section.

Undetectable viral load and a high CD4 count in the infected male partner can offer a relatively safe option if linked to timed ovulatory intercourse. However despite the percentage risks for a significant number of couples it would not be appropriate or they are unwilling to abandon the use of condoms for fear of infecting their HIV negative partner.

A low rate of Hepatitis C transmission - 2.9% - meant that whilst this was still a factor for consideration when planning to have a family, it was not seen as crucial as HIV infectivity.

Lara then outlined the main options for assisted conception, such as 'sperm washing' or the use of 'donor sperm' available to HIV sero-discordant couples .

Briefly, the main options were:

Artificial Insemination with partner's "washed" sperm.

The technique is based on the assumption that HIV infective material is carried primarily in seminal fluid and not within sperm itself. The HIV infected seminal fluid is separated from the sperm cells by centrifugation (spinning) and a swim-up technique ("washing"). The washed sperm is then combined with artificial semen solution, tested for HIV viral load and, if negative, inseminated into the woman when she is ovulating. There is the possibility that the viral load of the washed sperm may test positive, in which case this procedure would need to be repeated.

Artificial insemination with donor sperm

In this situation, a donor, who is anonymous and will have had a number of screening tests and counselling himself, provides the sperm. This prepared sperm is then inseminated into the female when she is ovulating. For convenience and practicality the woman's ovulation is often regulated by the use of an ovulation inducing drug.

Intrauterine Insemination (IUI)

In this technique giving ovulation-inducing medication to the woman stimulates egg development and then prepared sperm is injected via a soft tube placed in the cervix.

Lara concluded with the observation that in the near future more assisted conception centres will accept HIV/HCV discordant couples on to their programmes. At present this treatment is not available under the National Health Service, but she feels sure that this will be challenged, since The European Convention of Human Rights Act came into effect. It States :- **'A Person Has The Right To Marry and To Found A Family.'** This will now make it easier for UK citizens to challenge the NHS on such an issue.

A number of questions were put to Lara from workshop attendees, with couples expressing

despite the percentage risks for a significant number of couples it would not be appropriate or they are unwilling to abandon the use of condoms for fear of infecting their HIV negative partner.

...with careful monitoring of viral load and CD4 counts allied to the practise of intercourse at ovulation, some couples had managed to conceive without HIV transmission from male to female partner.

frustration at the current lack of accessibility to assisted conception programmes - particularly sperm washing - which remains unavailable in the UK through the NHS.

Some attendees shared their own experiences of starting a family, detailing how their frustrations with assisted conception programmes - the insistence on pre-treatment counselling for both partners, irrespective of all previous counselling sessions, the intrusion they felt into their personal lives, etc, had led to their deciding to go it alone. With careful monitoring of viral load and CD4 counts allied to the practise of intercourse at ovulation, some couples had managed to conceive without HIV transmission from male to female partner.

Mike O'Driscoll, a Haemophilic with HIV and HCV then gave a talk on his own experience of starting a family, the expansion of which was curtailed following HIV diagnosis in 1985. After the birth of his daughter, the options for assisted conception were much more limited than they have since become, leading to Mike and his wife exploring the option of adoption.

Having made a good initial impression regarding their suitability as prospective adopters, Mike outlined how the revelation of his HIV status changed the attitude of the adoption panel. The couple were subsequently turned down owing to the perceived terminal nature of the HIV diagnosis.

After some time had passed, the couple investigated the possibility of long-term fostering as a way in which to - if not expand their family - then at least to make use of the parenting skills they had developed with their daughter. Subsequently they contacted a private fostering agency, and, after a year spent training in various aspects of caring for children, they were approved as foster carers. Mike spoke about their experiences as carers since being approved, outlining both the positive and negative aspects of the job.

Among the latter he cited the difficulties one might encounter in dealing with the birth parents; the emotional baggage a child might already have accumulated prior to placement; the problems arising from this last point - anger and aggression directed towards the carers, difficulties at school, in social behaviour, at fitting in with the carers' family, etc; the frustrations at the length of time it took to get the child's social services department to take action or even to arrive at decisions which might impact on the child's future.

On the positive side, he noted the close bond that can develop between carers and child; the immense satisfaction to be derived from seeing a damaged child make progress - for example, an undernourished child gaining weight, making progress at school, developing meaningful friendships with other children; learning to trust and respect rather than fear and be suspicious of adults; developing their own interests and taking pride in their own achievements.

Mike concluded his talk by emphasising the differences between adoption and fostering - with the latter, the legal responsibility for the child's welfare remains with either the birth parents or social services, depending on whether the child is subject to a protection order, whilst in the case of an adopted child, the adoptive parents take on the full parental responsibilities that would normally accrue to the birth parents.

He pointed out the need for prospective carers to find out as much information as they could about fostering prior to training, and for them to be realistic about the difficulties the job entailed. If at that point they remained undeterred, he said he was sure they would find it a very rewarding experience.

A few questions were raised from attendees, mainly asking for clarification on the differences between adoption and fostering. Having answered these, Mike offered as a first point of contact, the main telephone number the Fostering Network (formerly the National Foster Carers Association): 020 7620 6400

Email: **info@fostering.net**
Web site: **www.fostering.net**

Some thoughts from a parent with experience of sperm washing....

a) Doing it naturally is a choice most health professionals are scared of and will not help with, I suppose they do not want to be seen condoning what society sees as immoral behaviour.

b) Surely it is better to have support and information. If that is the choice you make as it can help to understand when to have unprotected sex and stuff like having a sperm count and a woman checking to see if she is fertile....no point doing it if you 'aint got no tadpoles!

c) The process of sperm washing is invasive, expensive and very clinical. OK as long as people know that but it can be soul destroying.

d) Chances of a baby actually being conceived through sperm washing is very low, lower than by "normal" assisted conception.

e) If you make a baby naturally are you going to find out the mothers HIV status if she is negative before conception? if so...will you terminate the pregnancy if she is positive?

f) Is having a child who is HIV positive somehow the worst thing in the world or will you love that child as much as one who is negative and help them live with it?

g) Other babies are born with stuff as bad and worse.

h) Should you tell health carers if you are positive and making a baby naturally? Will they be OK and support you or will they freak out and suddenly the whole of the NHS knows and treats you like shit?

i) Lots of people with haemophilia and HIV have had/are having babies through unprotected sex, they just do not tell people! One centre director I spoke to said he knows of at least 19 babies born to patients at his centre.

j) People with haemophilia and HIV also have unprotected sex but once again do not tell many people!

the cost of sperm washing....

One of the main Assisted Conception Units for people with HIV is based at the Chelsea and Westminster Hospital in London. They produce a price list for their sperm washing programme and the current charge for a basic package is around £2,500. There may also be additional costs if fertility problems are identified as part of the process. Apart from this, if you don't live within easy reach of London, travel costs and overnight accommodation have to be taken into account. If you are living on income related benefits this may seem prohibitive but there are organisations that could assist you.

If you are a registrant of the Macfarlane Trust, the Trust will help with travel costs, accommodation, meals and other expenses incurred in order to access the treatment, however they will not pay for the treatment itself or any fertility tests arising.

Your Primary Care Trust (PCT) may fund your treatment. Most PCTs do not pay for fertility treatment, however it can be argued that sperm washing for people with HIV is not a fertility problem but an HIV prevention measure. Some Trusts may be willing to fund the treatment from their HIV prevention budget (if they have one!).

The problem with this is that disclosure of your status to the Primary Care Trust is necessary and some people do not want to take the risk of staff at their local Trust finding out that they have HIV.

If you do decide to try and get your PCT to fund the treatment, the Haemophilia Society can provide supporting letters on your behalf to pressurise the PCT and can also get other related organisations, like Birchgrove, Terrence Higgins Trust and the National AIDS Trust to do the same. This has been very effective in the past, for example in resolving a funding issue about hepatitis c treatment.

If you would like further information on sperm washing or any issue relating to HIV or HCV, please don't hesitate to contact me on FREEPHONE 0800 018 6068 or email: babs@haemophilia.org.uk

Babs Evans, HIV/HCV worker

...there may also be additional costs if fertility problems are identified as part of the process.

Sperm Washing in the UK

A Report from the
British HIV Association (BHIVA)
9th Annual Conference
April 2003

Richard Oakley

In April I attended the above conference in Manchester on behalf of The Hat Trick Group and Macfarlane Trust, it is the fourth time Hat Trick have sent a delegate and my second attendance at conference. The programme consists of lectures and research abstracts by clinicians covering a variety of issues, concentrating on the latest treatment strategies and research outcomes. Delegates are mainly from a clinical or scientific background but also include representatives from community groups and HIV charities, pharmaceutical companies form a large presence at conference and are major sponsors of the event. The Macfarlane Trust Social Worker and two Haemophilia Society representatives, one a community scholarship, also attended.

As a co-infected individual who has no medical background some of the information can be confusing, but with experience and through talking with other delegates it becomes easier, oral abstracts are also included in the programme resources enabling a greater understanding of presentations. Many of the research presentations, however, are inconclusive as stand alone pieces of work. BHIVA produces treatment guidelines on HIV and co-infection with hepatitis A,B and C which can be found at www.bhiva.org .

Many presentations were made at the conference that have relevance to myself and other registrants of the trust, below I shall do my best to report on these in a way I understand and hopefully in a manner most readers will find helpful.

Sperm washing in the UK

Since 1999 Chelsea and Westminster Hospital have run a sperm washing programme, few centres in the country run this service and health authority funding remains limited. Conclusions: "sperm washing in a specialist centre is safe and effective as a risk-reduction treatment. Lack of NHS funding for this service may force couples to consider unprotected intercourse. Health Authorities must address this issue". My conclusions: considering the high cost and invasive nature of the process I was disappointed that only fifteen children have been born using this programme, that is a birth rate of 10.6%.

Decisions around having children are emotional and difficult for us all, I cannot help feeling that we are somehow considered "bad" if we decide to have children on our own because of the virus we live with, a number of people living with HIV have made babies the natural way and other alternatives exist such as artificial insemination by donor and fostering. None of the alternatives are easy but it would be good to hear the issues debated without the morals. I am concerned at the cost and emotional effects of the process, to spend thousands of pounds with a 10.6% chance of having a child is a big deal. As I understand it the MFT do not fund sperm washing for individuals but may help with ancillary costs such as travel and hotel stays during the process.

An estimation of the UK demand for fertility services in HIV -positive couples.

The same hospital has also investigated the demand for assisted conception and conclude: "The demand for fertility services in HIV-infected couples is high. Our survey reinforces the need to improve current services to meet the demand and improve the information available to referring physicians,

" My thoughts on this are much the same as above, this report states the reduction in vertical transmission (mother to baby) of HIV from 20-30% to 1% and this would seem to "encourage HIV positive women to consider their reproductive potential." Well I never, HIV positive people want to have babies! Seriously, what do any of us do if we want to discuss this in a sensible way with supportive health professionals? I know that my experience when asking for support was dreadful, my centre were less than helpful and the "infertility clinic" they referred my wife and I to wanted to put us on a two year waiting list before even considering to look into any treatment.

Well I never, HIV positive people want to have babies!

Some haemophilia nurses have produced a leaflet setting out the options but steer clear of saying anything that may be thought of as controversial, in other words there are ways of trying to conceive naturally that minimises the risk of transmission but it's just not considered by people working in the NHS. Many registrants of the trust, and indeed many other people with HIV, have conceived naturally and are busy getting on with their lives, but it is the love that dare not speak it's name. I am not saying it is easy and I am not saying it is the decision everyone should take but I am saying it is an option and we should have some support if we want it.

Fears for HIV motherhood hopes

A small study has added further weight to evidence that women who have HIV find it far more difficult to conceive.

But it offers brighter news to HIV positive men who want to father a child. The research, carried out in France, found that only one out of ten HIV positive women given fertility treatment managed to get pregnant.

The precise reason why this is happening is unclear, but experts say a variety of factors could be at work.

They say that women who have had other sexually-transmitted infections such as gonorrhoea or chlamydia, which can harm fertility, may be more vulnerable to catching HIV when they have sex with an infected partner.

The virus itself - or perhaps anti-retroviral drugs taken to keep it under control - may also be having a detrimental effect on fertility.

Many more couples which include an HIV positive man or woman are now attempting to have babies.

'SPERM WASHING'

The wide use of modern anti-retroviral drugs has extended the life span of HIV patients, and modern techniques have radically reduced the risk of transmission from father to mother, or mother to child.

The research, published in the journal Human Reproduction, was carried out by Dr Jeanine Ohl at the Centre d'AMP de Strasbourg. They carried out assisted reproduction techniques on 57 couples in which at least one partner had HIV.

Sperm from the HIV positive men was "washed" to virtually eliminate the chance of the virus being transmitted. A third of the 39 couples in which the man was HIV positive managed to conceive a baby this way.

However, only one of the HIV positive women became pregnant, even though standard and normally highly successful IVF techniques were used.

'SURPRISED'

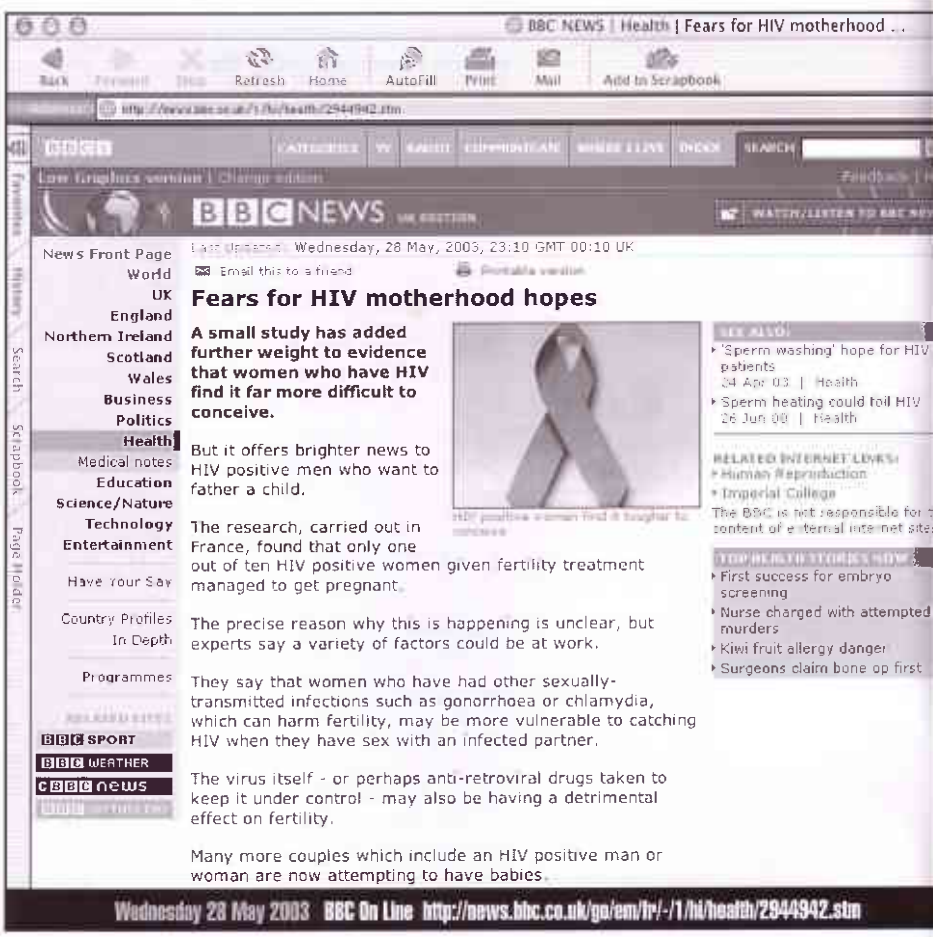
Dr Ohl said: "I was very pleased by the good results for men, but surprised at the poor results for women, which I did not expect.

"Some research has found evidence of premature ovarian failure in infected women although this would need confirming in a larger study. "On the other hand, in developing countries young infected women become pregnant easily. We have to determined whether the virus has created an additional negative factor."

Dr Simon Gregson, from Imperial College London, has studied the fertility of HIV positive women, and says there is now firm evidence that they find it harder to conceive.

...however, only one of the HIV positive women became pregnant, even though standard and normally highly successful IVF techniques were used.

He said: "Some studies have suggested that fertility is reduced by as much as 30% to 40%. "It is possible that the virus is more easily transmitted to a woman who has had an STD which has already damaged her fertility. "But the virus itself may be causing an extra effect."



Further Reading and Information

Starting a Family- A Guide for people with HIV.

"As a man or woman with HIV, having children seems more complicated than before you were HIV positive. Many people with HIV do have children and with good HIV and maternity care, people can have healthy children and stay healthy themselves. As someone with HIV, having children could be an essential part of living life fully."

This booklet is for you if you are HIV positive and have questions about starting a family. It covers options and choices and includes information on HIV testing, affects of HIV medication and sperm washing.

Available from Terence Higgins Trust.
Tel: 0207831 0330 E-mail: info@tht.org.uk

Haemophilia with HIV- You CAN THINK about starting a family

A leaflet containing information designed to assist you in making decisions around having children. Covering assisted conception techniques, what happens for both of you, risks of transmission and counselling. It also contains quotes from people who have considered assisted conception.

"I know this is a terrible thing to say but I felt really resentful about him having haemophilia. I never told anybody how scared I was about becoming infected with HIV"
" We are delighted with our baby but it put a far greater strain on our relationship than either of us envisaged."

It advises contacting your Haemophilia Consultant at your centre for a referral to an Assisted Conception Centre.

Obtain booklet or further information from:
Babs Evans at the Haemophilia Society

"they should make a decision as to which option to choose based on balancing the chances of conception against risk of HIV transmission..."

Promoting Safer Sex Among HIV + Youth with Haemophilia

A study conducted by at least ten medics from 1993-2003, based in the USA. The goal of the project was to develop and evaluate theory based interventions designed to change sexual behaviour and promote safer sex practices of HIV positive young men with haemophilia to prevent transmission to sexual partners and offspring. Safer sex was described as complete abstinence, consistent condom use, or something called "outer-course" (which we in the UK call masturbation or hand job).

The whole study looks at behaviour change and seems to forget that we are people with natural urges. It doesn't give much help for the young men who actually want to start a family, or safer sex and conception. For the full report see " Haemophilia (2003), 9, 214-222 RB Butler et al. Blackwell Publishing 2003

"As someone with HIV, having children could be an essential part of living life fully...."

Conception in HIV- Discordant Couples

"Treatment of Haemophilia"
May 2002 No.26 WFH JT Wilde
As the treatment of HIV has now become more manageable and patients have an improved quality of life and life expectancy many people are now considering having children and starting a family. This paper discusses the relative merits of alternative methods of conception that are available.

It concludes that HIV discordant couples (where one is positive and the other is negative) should be offered appropriate counselling and advice before attempting conception. They should make a decision as to which option to choose based on balancing the chances of conception against risk of HIV transmission. Of the two main alternatives, artificial insemination with washed sperm is the safer option although the conception rate for each attempt is about 10%.

The other option being "timed ovulatory intercourse" which is not without risks. The paper concludes by stressing that it is crucial that appropriate, effective strategies are developed to protect transmission of HIV in discordant couples who are wishing to conceive.

dear diary...

Week 26

A week to celebrate as the world cup starts on Friday!! I see my HIV doctor in Brighton and it seems the combination is still working 2 months in which is relief, I do not want to change it again when I am on interferon. Still struggling to get up to get food to take with them and having an meal late in the evening is starting to annoy me. The stomach bleeding has definitely stopped which relieves him and I am back to one factor VIII injection when I do the interferon. I tell him that I am looking forward to the world cup, it will get me up early and I can fit breakfast and tablets in at half-time. Has anyone else used football as a adherence technique I wonder?

Week 31

...and lots has happened, England beat Argentina, (Beckham is a God and Owen much more subtle at falling over than Rivaldo!). Brazil were glorious and deserved to win the thing and for a fleeting moment I thought England had a chance of being world champions. Ireland played magnificently at times, Senegal were great fun but the Koreans seem to have the biggest party of all. Oh and I was PCR negative at 24 weeks. 30 weeks done. It really is a grind now, the cycle of get up eat, take tablets, watch football, go shopping or see friends, eat, take tablets, go to bed has got me through 5 more weeks.

Thinking back over the last 20 weeks or so and reading this again my side-effects seem to come in waves of a week or two then a change. Some weeks I have little appetite and then it returns. The same with sleeping, some weeks I can sleep without any tablets to help and others I just lie awake for hours. The stomach upset and problems with wind have not been around for a month or so and hopefully will not come back. Getting more arthritic type aches the last few weeks though. I still hate doing the interferon injections but the walk up the hill every Monday to the ward must be helping me get fit.

Week 44

It is over ten weeks since I wrote anything and I have tried to spend the summer resting and recovering some strength. After what felt an extremely long September with 5 Mondays in it I have finally got to the last month of the treatment. This is the 44th week and there are 4 more injections to go. Symptom of the week is insomnia, not my favourite, and I have increased the number of nights taking pills to help me sleep.

I have calculated my first drinking day as well. My friends have been asked to keep this evening free and mark it in their diaries. The joy at finishing this course will be overwhelming I know and I am getting very impatient that I cannot accelerate time or take an injection every day to get through the last four. My CD4 cells have finally stabilised but below 200 so I keep having to breath a noxious gas called Pentamadine every month. Next one is on Wednesday and I imagine that will continue for about 3 months after I finish the treatment. I am still hoping to get away without any serious adverse reactions before the end as although it has been hell I feel I have been lucky to get this far without even worse problems.

I have had an image of how to describe this to others - it is like getting on the slow train home, the one that stops 100 yards before every station and waits ten minutes because the wrong type of sun is shining or whatever. At the moment I am just a few stops from the end, exhausted and just want to get home and sleep. On a more positive note I am also tying to think what I will do when the treatment finishes. My hair is sill straight but I guess will go back to being curly when I stop the interferon and the side-effects come for a few weeks and then swap round to another group returning at a later date. And I am just very tired of the whole kit and caboodle - I want it to get off this dam train!

Week 47

The night before the last interferon injection and this week has been really good so far, I have actually felt energetic for most of the week. Just the thought of only having one left has been a high all week.

Week 50

Well I took a chocolate cake up to the ward staff. They seemed pretty pleased although it was quite busy there so I did not get much time to chat. To make up for feeling so good in week 47, inevitably I had a really rough last week on that dreadful stuff. The first Monday without interferon was very strange as well. But it felt so good not to go to bed at 4 in the afternoon and to feel okay on a Tuesday morning. This week I started drinking proper tea again and realised that I had stopped drinking milk as I had not got any or bought any for months.

Week 52

Life is fantastic - it has been amazing how much comes back. Food tastes so much better, I can drink tea and coffee and - wonder of wonders - I have even allowed myself alcohol again. I started with a quiet meal with friends and a few glasses of wine, fearful that I would end up completely slaughtered. I really do not care if it works at this stage because of how good it feels to have stopped taking the horrible stuff. Jeez was it hard work....

Next Issue...
The Final Result

The Penultimate Instalment of the Peg-Interferon Diary...

...the Story Continues

"It is over ten weeks since I wrote anything and I have tried to spend the summer resting and recovering some strength..."