

Birchgrove

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to tell....

In this issue of the Birchgrove newsletter we aim to explore peoples experiences around disclosure. Should you tell people about your HIV, your Hepatitis C, or even your Haemophilia/Bleeding disorder? What are your experiences of telling people about your health status? What are your experiences of not telling people about any of them? How do people react when you tell them about your HIV? Are there any tips for Birchgrove readers about telling friends and family? What happens after you have told certain people? Has this changed your relationship for the better or worse? Is there a right time to tell and if so when? How do you do it and how does it make you feel? Do you feel that certain people should know? What do they do when they are told and how do they handle that information? How do you tell partners or children? Does your status affect your employment and do you tell employers or fellow colleagues?

Obviously we can't answer all your questions and everyone approaches this issue differently but hopefully some of the articles will give some food for thought.

stopping the secrets...

My husband is an HIV+ HCV+ haemophiliac. He was diagnosed with HIV at the age of 11. We met at University in 1998, and on our third date he told me he was HIV and HCV+. I was very upset, partly as I already knew that this was the person I wanted to spend my life with and it was very upsetting to believe that would be cut short so early in our relationship. At the time he asked me not to tell anyone else, as he was not sure about how other friends would manage.

Shortly after our wedding in 2001 it seemed more appropriate to stop keeping his medical status a secret, particularly from my family and our closest friends. My family reacted extremely well, my mother wasn't surprised or upset even though we had both been lying about it for 3 years. She has been extremely supportive since. We are still close friends with those who have been told - ***the most difficult part of telling them is trying to explain that neither of us are about to die and that it is best just to get on with life and enjoy what there is.***

HIV is more difficult to disclose than HCV simply because of the stigma. In particular as my husband became HIV+ through a blood transfusion there seems to be a certain degree of people taking the disclosure well because it is "good AIDS." However, we have generally had the experience that we are underestimating our friends by the way we have expected them to react, and everybody has coped very well.

The author of this article asked to remain anonymous.

...Or not to tell

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Timing is everything

So you meet someone at a party, you like each other, sexual tension is high, you're horny and up for it. You've both had a lot to drink and you invite her/him back to your place. The sofa becomes a hot bed of passion and before you know it you're naked with this gorgeous person. There's something you've forgotten...HIV.

You know you're not going to do it without a condom but you feel you ought to tell her/him. She/he seems cool about it and hasn't lost her/his enthusiasm. You spend the next few hours in wild abandon.

The next morning when you wake she/he doesn't seem as keen and in fact she/he's very quiet. You part with a kiss and a promise that you'll call but she/he never seems to be in when you do.

To tell or not to tell?

If you're really just out for a good time and a one night stand of fun and passion you may want to consider whether or not to tell. If you're going to use a condom anyway perhaps you don't need to face the disclosure issue?

On the other hand - what if the one night stand turns into a relationship? If you've been having sex with your new partner for weeks she/he may feel betrayed when you do tell her/him. Sometimes people can get into this situation and end up living a lie with their partner for years and years.

Desperately seeking...

If all you want is a loving relationship with someone who cares for you, the hardest thing in our busy lives is of course meeting that person. But once you've cracked that, when do you tell? On the first date? After a week? A month? Three months?

The main thing is to give her/him a chance to get to know you and how long that takes will depend on how often you get to see each other and how much talking you do.

Location, location, location

So now you've decided to break the news but where's the best place? Here's a few things to consider:

1. If you do it at your place you can't leave if you need time alone afterwards
2. If you do it at her/his place, she/he can't leave and may not feel comfortable asking you to go if time is needed to think things over

3. If you're in a pub people may overhear your conversation
4. If you're in a restaurant you can guarantee the waiter will interrupt just at the crucial moment

A top tip!

Go for a walk in the park.
The advantages of this are...

1. You can be side by side and won't have to look her/him in the eye when you reveal your status
2. You won't be overheard
3. She/he will be able to hug and reassure you
4. Embarrassing silences or thinking time are easier when you keep strolling along
5. You can end your date and make arrangements to meet again without either of you feeling pressurised
6. There's usually a cafe in the park for when you're both ready to sit across a table

Be prepared for the questions

Once you've disclosed your HIV status there may be lots of things to ask you about. Maybe straight away or over the next few weeks.

Get your answers ready for some of the common ones:

How did you get it?

How long have you had it?

Are you OK?

They'll be a cure soon won't there?

And afterwards...

Many people living with HIV have gone through this process and ended up in long-term relationships with a partner that cares for and loves them

What if it doesn't work out?

Firstly, it may not be anything to do with HIV. People enter into and end relationships all the time. If it is to do with an attitude about the virus, this is HER/HIS problem, not yours. It's really scary to take the risk of disclosing to someone and congratulate yourself for doing it. Next time it will be easier.

Disclosing to new partners

...what if the one night stand turns into a relationship?

Putting a stop to the lies...

Over the years the secrecy surrounding my HIV diagnosis has consumed me. In the early days especially as the stigma and fear was immense. Having this virus has changed me in many ways but I never expected it would turn me into a liar. I have lied to my family and friends and people very close to me for years and I became extremely good at it. Developing tactics and quick responses to any questions, alibi's and cover-ups so that no one would suspect. Why? Because I didn't want anyone to know. Why? Because I thought it would change my relationships with people for ever, I would lose any control I had over the situation, It was my problem not theirs and mostly I feared that people wouldn't understand and treat me differently.

So what has changed to make me think any different? I suppose the fact that there is some hope of a future with today's drugs, and I don't want to spend the rest of my life lying to people that I care about and spend my life with.

Having spent a lot of time talking to other people with Haemophilia and HIV has helped me get my head around talking about HIV as I would any other aspect of my life.

I told one friend shortly after my diagnosis and I regretted it as looking back it freaked him out almost as much as it did me.

I told 2 friends 6 years ago as they were going to live abroad for a few years. I told them because I didn't think I would be alive when they got back. Looking back it was heavy load to dump on them, they were very supportive although shaken by my news, but urged me to share this with others. So over the last 5 years I have been telling my friends, very slowly, one at a time. Its never easy and however many times I played over the scenarios in my mind it never worked out as planned. There is a never a right time. There are plenty of wrong times to do it but never a right time. I could always think of an excuse not to tell them. One by one though it does get easier. I am getting used to now seeing my friends look at me in disbelief, see the sadness on their faces, the hugs that follow, that silence as they try to make sense of it, the endless questions that follow, the reassurances that I have to give, the anger they take on and then when it all sinks in and again disbelief that I have carried this secret without telling them, without sharing it.

So how has it gone so far? I feel better in myself. I feel happier being honest with my friends for the first time in a long time. I do not have to keep up the pretence and it makes life easier for me. I am lucky in that the people I have chosen to tell so far have been very supportive and understanding. But what impact has it had on them? I would like to think it has made our friendships stronger overall but individually

there have been similar reactions. Everyone I have told has reported lying awake all night unable to sleep as they have tried to make sense of it. Everyone has come back with endless questions after they have thought about it. I think they have all needed support from me in trying to help them get through it. Every occasion has been emotionally draining for all parties. One friend had to take the next day off work, as he was so upset and angry. One friend phoned me the next day to tell me he had been awake all night remembering a memory he had. In 1986 when a government "don't die of ignorance" advert came on the TV, when we were with a crowd of mates, he remembered kicking me and saying pay attention this adverts for you. I didn't even remember myself as I think I blocked a lot of things out in those early days of HIV. We have laughed about it now.

One friend said to me some months after I had told him that he it really depressed him, he said he felt like I had died the moment I told him and he went through some weird mourning period. Another said that he was so pleased I had told him now and not years ago, as he didn't think he could have handled the news when the prognosis was an imminent mortality.

Everyone has needed support themselves and I have tried to help this process by telling them the people that know and don't know. They have been able to go and talk to someone else about it that has gone through the disclosure period and the thought process that goes with it. I have given them reading material as most of them have gone through an initial quest for knowledge as so many of them knew very little about HIV. I have given them phone numbers of HIV phone lines where they can phone for support and information themselves. I have always, where possible told friends 2 at a time, i.e. couples, as I realise that it is a heavy load to drop on somebody if they haven't got someone to talk about it with and human nature is that they will want to talk about it.

The common question everybody has asked me, once they are assured I am not going to drop dead in the next few weeks, is why haven't you told me before? My answer is that they never asked me. I have never lied about having Haemophilia and have worn a red ribbon for years and still nobody ever asked me. I always assumed it was because they didn't want to risk asking me if they couldn't handle the answer they didn't want.

The journey is far from over and I have a few more on my list to tell but it does get easier with practice and I haven't regretted it once so far. After all what are friends for?

by Paul

Disclosure in the workplace

Telling your boss or work colleagues about your HIV status can be a daunting prospect. As someone living with HIV who has changed jobs since my diagnosis I have had to face the dilemma of who to tell and when to tell them on a number of occasions. Sometimes this has been a positive experience and at other times a negative one.

When I was diagnosed with AIDS in the early nineties I was working for a small Housing Association as a Supported Housing Officer. In common with many people who are newly diagnosed I was terrified of people finding out. For the first year there were only two people who knew, my partner and a close friend who lived many miles away, so it was a big secret.

My job involved me living on site and working very closely with one colleague. Before I found out I had AIDS we were very close and talked about everything but I didn't feel able to tell her about my status. I found it very stressful to maintain the friendship we had developed and it was difficult to tell the lies that I needed to in order to cover up my activities and fears. On my days off I would sometimes go to Positively Women or have a hospital appointment and I hated having to lie the next day when my colleague asked how I'd spent my free time.

As I found out more about AIDS and HIV, as I learnt to call it, I started to worry about where I would die and what would happen. I was given a flat to live in with my job and was concerned that when I got ill and was no longer able to work I would also be homeless.

I started to look for jobs with local authorities as I thought I would be treated fairly when I got ill. However, I was very worried about what the situation was with regard to my status. I found out that I didn't have to tell future employers that I had HIV and in 1994 I got a job as an emergency officer and moved out to my own flat.

In my new workplace nobody knew I had HIV and I was quite reserved compared to my colleagues who talked openly about their lives. Some of our clients had AIDS and one day I had a blazing row

with another worker who felt we had a right to be told if someone had HIV. When questioned he said it was so he could wear gloves whenever he visited. To me it was as if he was saying "I wouldn't touch you without a pair of gloves on". Over the next year or so I got more and more tired and struggled to do my job. I did everything I could to avoid going out on emergency calls and would persuade my colleagues to go instead. I got a reputation for being lazy. One day I was out with a colleague and we were going on a routine visit to someone who was dying of AIDS. I had been to this man many times before but on this particular day I just couldn't face him. I asked my colleague whether she minded going alone and I wonder whether she thought it was because I was prejudiced against people with AIDS!

Towards the end of 1995 I developed a chest infection and was off work for three weeks. Our service was 24 hour and so people had to work over Christmas and New Year. I was due to work on Christmas Day but despite the antibiotics I'd been given the infection got worse and I got weaker and weaker. My colleagues knew I didn't want to work at Christmas and started making comments about a 'fake' illness. I tried to combat this and continued to go to work but a few days before Christmas I could barely get out of bed. I went to hospital and suspected PCP was diagnosed. I refused to be admitted and my family collected me with the medication I'd been given and took me home. I recovered and eventually returned to work but it was obvious that my colleagues didn't think I had been seriously ill.

In 1996 I was a member of the speakers team at PW and we increasingly had requests from the media. As my family and close friends knew I had HIV by this time I agreed to do an interview for a monthly women's magazine. It was to be published in two months and I began to worry about how it would effect me at work. My main concern was that our clients would panic and phone the council, particularly those who I had administered First Aid to, even though I was always extremely careful to cover up any cuts and sores on my hands and wear gloves. I went to see my boss and told him I had HIV and that it may

...it was difficult to tell the lies that I needed to in order to cover up my activities and fears.

...after all some of us had careers before we became people with HIV and in a positive working environment there's no reason why we shouldn't continue them!

become public knowledge. Imagine my surprise when instead of talking about our clients he asked whether there was anything he could do to help me continue in my job!

A few days after the magazine article appeared a national newspaper got in touch and I was interviewed. The result was a substantial article with photos so all my colleagues found out at this point. It was a relief not to be living with the secret anymore and some people talked to me about it and others never mentioned it. Eventually things settled down and back to as normal as possible, or so I thought. Years later I learnt that someone had complained to senior managers about employing a member of staff with 'AIDS' as an emergency officer and it had thrown the department into turmoil.

By 1997 I had been very unwell for some time and decided to start the new HIV drugs. I had a lot of problems with side-effects and colleagues were quite supportive. It was common practice for us to sleep at night in between calls, however I was so worried that my employers might be looking for an excuse to sack me that I didn't dare do this. I was constantly exhausted and suffering from diarrhea. I stopped taking the medication.

Although I had clients living with HIV it had been a small part of my job but in 2000 I applied for the post of HIV/HCV Worker at the Haemophilia Society and started work in the April. There was no medical form to fill in so yet again my colleagues didn't know my status.

I am still in post and am really enjoying my work. Some of my colleagues, other professionals and people affected by haemophilia and HIV know my status and others don't. It's not that it's a secret but neither is it the first thing I want people to know about me. My confidence was very low when I started work here and I felt it was important for me to prove my professional ability. Another HIV worker recently found out I had HIV and said "I didn't realise your job was a designated post." "It's not" I replied, after all some of us had careers before we became people with HIV and in a positive working environment there's no reason why we shouldn't continue them!

Babs Evans HIV/HCV Worker

Information that may help with Disclosure

Should I Tell?

A pocket sized booklet with helpful suggestions and thoughts to help people make decisions about telling people that you have HIV.

Available from Terrance Higgins Trust

Email: info@ttht.org.uk

Tel: 020 783 10330

When Opposites Attract

Living with HIV when your partner is HIV negative. A pocket sized booklet produced by THT as above.

Voices of Children and

Talking to Children are two colourful and informative booklets which can be obtained from the Children with AIDS Charity, Lion House, 3 Plough Yard, London EC2A 3LP

Tel: 020 724 9120 (£2.50 + p+p)

Talking to Children about HIV

Report on a workshop held at 'Something for the weekend' in Stafford 2002.

Available from the Haemophilia Society

WHY ME?

Published by Avert this is a collection of thoughts and stories from young people living with or affected by HIV/AIDS.

Free to download from the AVERT website www.avert.org

Positively Women- Jan/Feb 2003 Disclosure Special

Personal stories and resources.

347-349 City Road London EC1V 1LR

Tel: 020 77131020

Email: info@positivelywomen.org.uk

apologies....

To Gareth Lewis for not crediting him with his article "Something From The Weekend" in the last issue of Birchgrove.

We welcome contributions from all readers and will credit you or retain your identity as you wish.

HAEMOPHILIACS CAN'T BE GAY?

Society is moving toward greater gay-acceptance whilst medicine increasingly improves haemophilia treatments. In the light of these, **Mark Ward** shares an insight into living with both...

We all know that if we have a concern about our haemophilia or HIV, we can phone or have a chat with one of the unit staff next time we go. Ok. But what if we know we're also gay or bisexual?

Well, let me take you on a journey... Imagine you're sixteen years old, life's wonderful, exciting, yet seems very unstable; a never-ending cycle of education, what job you'd like to do, raging hormones, sport, TV, pop-music, fashion... and spots. And throughout (gasp), you get that familiar stirring-in-your-loins that you've had since puberty. Your mates all talk endlessly about the girls they fancy. Maybe you do too. Except that for you, it's slightly different; that 'horny little devil' takes-over when you see David Beckham or Enrique Inglesias on TV or when you see one of your cute young mates at the swimming pool. Yes, you might be bisexual or even wholly gay.

Big Deal! Everyone knows that society is more accepting of gays and bisexuals; there are lots of ways that you, as a young gay guy, can find advice and support - but only about being gay. Now try reading my story again but this time reflect on the fact that you're living day-to-day with haemophilia.

**"As a gay
haemophiliac
myself I've lived
a happily active
sex-life for
many years..."**

At worst we're encouraged to believe that we don't exist or, at best, that we can be haemophiliac and gay ... but we simply can't have sex.

At the moment, if a sixteen-year-old haemophiliac tries to talk to anyone because he feels he may be gay or bisexual, the subject is very quickly changed. This is because there is little in print that can help him or his advisors. No booklets or leaflets... Nothing in plain print to pick up and read - and learn. With no one to help and advise him with down-to-earth, practical knowledge, he's out there feeling confused and alone. It's not surprising that some feel like freaks. Thankfully, this picture is about to change forever...

As a gay haemophiliac myself I've lived a happily active sex-life for many years. I've been asked to write this article in the lead-up to the launch of a new booklet called "You Don't Have To Be Straight To Take Factor-VIII".

Aimed at gay or bisexual men with haemophilia/Von Willibrands/bleeding disorders, the booklet is a basic guide which raises subjects like safety during sex and sexual health in addition to bearing handy tips and good, sound advice in an open and honest, no-holds-barred way. There's also lots of useful contact information with phone numbers.

Published by The Haemophilia Society, the booklet, plus a supporting package of a fact-sheet and training for Unit Staff, will provide much needed help and advice for guys with bleeding disorders who may be questioning or exploring their sexuality.

We all know what it's like to have bleeds and pain; maybe we're taking tablets just to stay upright... but hey, what about sex? We're all men and sometimes it's easy to forget that, whether gay, bi or straight, our needs are just the same. We live in a community which includes gay/bi guys in addition to haemophiliacs; Who we are... Gay and Haemophiliac... is simply another part of that community wishing to be recognised.

"You Don't Have To Be Straight To Take Factor-VIII" can be obtained by contacting The Haemophilia Society on 0800 018 6068, emailing info@haemophilia.org.uk or can be downloaded from the website at www.haemophilia.co.uk

"As a gay haemophiliac myself I've lived a happily active sex-life for many years..."

The Peg-Interferon Diary...

...The Story Continues Weeks 14-20

dear diary...

The next 6 weeks are hell. I feel awful the whole time. Too awful to write this diary. I have missed lectures regularly on my course, if I stay up beyond 10 I am exhausted the next day and what's more my stomach hurts. At first I thought it was the lopinivir as it has gastric side effects. But then I thought it felt like a bleed so I took factor VIII. Eventually by taking factor VIII every other day the pain subsides, it is the PI bleeding problems. For the next 6 weeks I am on 4 times as many injections as I was before I started the treatment (4, 3IV 1IM:1, 1IV) and four times as many tablets per day (4:15). Life is awful and all I keep hoping is that the bleeding will stop. Seem to do nothing apart from visit the occasional friend to moan about how bad I feel.

The 'not drinking' is no longer a problem - I hardly feel like drinking water never mind beer. Everything is exhausting, getting up and making breakfasts is tiring, showering and dressing is, even making a drink to stave off the dehydration is exhausting. I get annoyed very quickly and am really fed up. I am even fed up that I have to pee so often which is madness. The combination seems to be working after a fortnight but it is hard work getting up to eat every morning when I am so shattered. Struggle to do some course work and just about make an essay plan. Struggle in to the college library for a day and do all the background reading and get quotes for the essay. Had hoped but not expected to do enough for both essays but it is too exhausting. Wonder if I will be feeling okay to go to the places I've planned to.

Week 20 is a mile stone in more ways than one. I go 3 days without stomach pain and just maybe, maybe the bleeding is stopping. I finally get the 12 week PCR and it is negative. Well actually I feel so bad that part of me would quite like it to fail so I can stop taking it all. However it is working, this is the best chance I have to lose the bug. I refuse to be beaten by these drugs. It feels good to have done 20 weeks at least. I also get away again, this time courtesy of Roche pharmaceuticals who offer me a place at the EASL conference as a journalist. Does this diary and a few articles for Pos Nat and the Birchgrove really count as journalism?

Stomach pain is pretty much okay and I find Madrid another warm and good place to be. Perhaps what those on Interferon really need is to spend it in warmer climes relaxing in hotels

with restaurant food laid on. Now how can we get the NHS to pay for that? Finally see Guernica at the Reina Sofia (it was shut last time I was here) and am impressed by some Dali pictures which surprises me. Not the dripping watches or weird stuff but just a picture of a woman (his wife?) looking out over the sea through a window. Back for the weekend and finish one essay that is due in Friday. Sadly I have another one due in then too. After finishing it though I am too shattered and take 2 days to recover. Abandon idea of finishing the second one in time and ask the registrar at St Thomas' for a note saying I'm not particularly well at the moment and can I hand the essay in late. He is happy to do it after reviewing my notes. I thank him and wish him luck in his own impending exams.

...life is awful
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Week 23: I am certain that the stomach bleeding has stopped now and I am chancing the once a week factor VIII injection rather than twice as I did last week. It works, I go off to Edinburgh for the weekend to do a talk and see a friend in Glasgow taking factor but do not need it. It is great to see the friends.

Week 24 and this is half way. Oh does it feel good to have got here. From now on there will always be less to go than I have done. I put some plugs and a light in for a friend, Clea who has just bought a flat. Try not to look too surprised when the light actually works first time but am chuffed to bits. She is pleased at having a proper light in the kitchen as well. Get "connexed" on the way to the hospital as the trains all seem to have died. Give up and re-arrange for tomorrow.

Robert

The Macfarlane Trust Partnership Group

About three years ago I was having a 'less than friendly' phone conversation with Ann at MFT when she mentioned a group that was being set up by the trust to get some input and involvement from its users. She asked if I would like to attend the next meeting and I decided to give it a go, up until this point I had kept pretty clear of other people with haemophilia and HIV, limiting my contact to occasional calls to Birchgrove. I sensed that Ann was maybe inviting all the disgruntled people she spoke with to these meetings as part of a cunning plan, a plan so cunning I could not work it out so I thought I had better find out for myself.

To be honest I have spent the last twelve years of my life being disgruntled with the MFT, I felt then and still do, that the governments whole response to our infection was inadequate and we should have been compensated properly and with some compassion. Instead we were left with a hardship fund totally under funded and resourced to respond to the changing needs of those living with HIV, their dependents and families. To add to this insult the trust itself was, and this is an entirely personal view, mismanaged for years by some people who had either no understanding or inclination to really try and help us. So, I went to my first Partnership Group with a whole bunch of anger, glad at last to have an avenue to vent my considerable frustration.

The present government is very vocal about 'patient involvement' and I expect this message had reached the trustees of MFT. Whatever, the aims of the Partnership Group were admirable in my mind but would anything positive actually come out of my involvement or indeed the group itself. At my first meeting I found myself basically telling MFT what I thought of them and how they were nowhere near fulfilling my idea of who and what they should be. Over the next few meetings, attended by registrants and representatives of MFT/Haemophilia Society, more people with HIV came on board and had their turn at expressing anger and frustration.

The debate was often heated and some individuals, including Trustees of MFT/Haemophilia Society, were shocked and unhappy at the level of bitterness. To be frank some of them deserved to be shocked and unhappy because they perpetuated the old MFT and its often uncaring face with their arguments and attitudes. Me? I began to forge friendships and share pints with all sorts of odd balls, a bond was beginning to form and it was

great to share my anger and frustration with others put in the same position.

Looking at where the Partnership Group is at now I feel this period was absolutely vital to its growth. None of us could hope to think in a constructive and strategic way about meeting the needs of all registrants without unloading the anger first. Since those early days about fifteen of us have remained on the group and others have left, for whatever reason deciding it was not for them. The group presently comprises registrants, partners, a bereaved partner, HIV/HCV worker from The Haemophilia Society, Chair MFT, Chief Executive MFT and Social Worker MFT. It is open to all people personally affected by the trusts work and remains an open forum, just give the MFT office a call if you want to know more about joining. We would welcome the involvement of fresh faces, especially more partners, bereaved and men under 35!

This brings me on to the progress made over the years and the current situation. The Partnership Group is currently nearing the end of a review of its work and full details of what its aims and objectives are will be published in the newsletter. Everyone on the group felt it was time to sit down and work out exactly what it was supposed to be doing, if it was merely a talking shop then let us be honest and admit that. I think we all felt it should and could be more than that, as the MFT is currently undergoing a review of its services this seemed a perfect time to sit down together and do some proper planning.

A number of us have already met over the last six months with help from an external facilitator and we have a couple more meetings before we finish the planning process. It has been hard work but the plan is to decide how The Partnership Group can help the MFT prioritise support for registrants and for us, the people it affects, to have a say in their response.

We have already made real progress in some areas and I stress that none of us are complacent, we still have our righteous anger but are channelling it in a constructive way. The regime at MFT has changed, it is not perfect but the current Chair (Peter Stevens) has responded to us in a way that would be unthinkable from his predecessor, he has learned a lot over the past few years about the way some of us feel and I am sure he shares many of our frustrations about the situation, he also gets his round in!

"To be honest I have spent the last twelve years of my life being disgruntled with the MFT..."