

Campaigners speak: bereaved people searching for truth and justice

By Catherine Jackson

catherine.jackson@bacp.co.uk

Anger is a natural response to bereavement – but how helpful is it when that anger is channeled into a campaign for truth or justice? Catherine Jackson interviewed four people involved in high profile campaigns following the death of a loved one.



Jim Swire was propelled into the political limelight when a bomb blew up Pan Am Flight 103 over the Scottish town of Lockerbie on 21 December 1988. His daughter, Flora, was among the 259 passengers and crew who died and Swire, at the

time a GP, has spent the past 25 years fighting for the truth about what happened to be revealed by the UK and Scottish governments.

I don't remember much about the initial few days or weeks. I certainly couldn't work or anything. I was mentally paralysed.

I was extricated from the numbness and horror of it all by anger – anger, unfortunately, against the establishment because we knew that the plane had taken off from Heathrow, that Heathrow had been warned in advance, and these warnings weren't acted on.

My dear wife Jane seemed to understand that my trying to get to the roots of all this was a way of coping, which it was and still is. Campaigning is how I survive and will remain so until the powers that be cough up the truth.

Jane was just as shattered as I was, but her reactions were those of a mother hen. She tried to gather in the family as far as possible – we have another daughter and a son. I think she was probably relieved that I had got the bit between the teeth.

I think the fact that someone had done it made it easier than if it had been what we call an Act of God, like an earthquake. For one thing, I am a Christian and believe that God created the world as it is and when terrible things happen that is how God wills it. But he also gave us freedom to do good or ill and that freedom means that we have a choice to commit good or evil.

Someone destroyed the aircraft; it wasn't mechanical failure; someone hadn't just made a mistake. The fact that there was an element of human evil and of human failure enraged me and that helped me to cope with the bereavement, particularly because the two were combined. The terrorists involved had formed a plot but on top of that the government hadn't looked after its citizens and was hell bent on concealing how it had happened and the security failures that allowed it to happen. We have irrefutable evidence that the UK and US were in possession of knowledge that, had it been sensibly used, would have prevented the disaster and is still being protected from the public's gaze. The two Libyans were indicted for political reasons.

Most people seek revenge if they have been wronged by someone and they would like retribution. But that goes against God's teaching that someone who has done evil things is also capable of doing extremely good things in the future: you hate what he has done, not the person himself.

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All this has been overlaid by a need to campaign in a way of which Flora would be proud, to find the truth but also to behave honestly. That is one of the things I find it difficult to know: how much of this is honest and justifiable in a way Flora would have approved and to what extent I have overstepped this, to the detriment of the rest of my family. Jane realised early on I was going to have to do this, more clearly than I did, but that doesn't give you carte blanche to lay about you to the detriment of your family and others.

The trouble with a campaign is it isn't a part-time. You can't half do it. I have tried on a number of occasions to withdraw from the frontline but I have realised it only finishes when I am satisfied that the establishments of England and Scotland have

been reasonably honest about what they know about what really happened and have passed that to the public.

It is a weird way of grieving, a very anxious way of grieving, this curious, high profile way of coping with it all, but this is the only way I have been able to muddle through.

I have had the advantage of being busy in the past 24 years. Whether people have something to do with their time greatly affects their ability to cope and I have that and I am grateful for that.

Jane Swire is Flora's mother and Jim Swire's wife

I just tried to keep going for everyone's sake. I didn't want a public profile, I wasn't anxious to discover the how, the reasons behind the tragedy. That was not my way although I think it was helpful for Jim. My concern was how I was going to cope and how to do the best for the family that we have left. His way wasn't my way but I could see it was very important for him and that in itself was a way forward for us as a couple. Everyone has their own ways of doing their best to cope.

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Sometimes I think it's true that he has focused on the campaign and hasn't dealt with the grief but I think that is the only way he can cope. The good thing was attending the group, the 30-plus UK people who had lost close relatives. It was in no way a homogeneous bunch and everyone dealt with it in very different ways and that was also good – to see how we all were so different. There is no prescriptive way of dealing with grief.

Maybe for Jim it will be an enormous help to get the truth but for me possibly not at all. I am glad that there isn't a possibly innocent man in prison [Abdelbaset Ali Mohamed al-Megrahi, who was convicted of the bombing, was freed on compassionate grounds in 2009 and returned to Libya, where he died in in May 2012] – that was a terrible worry. But the very thing I want, to have my lovely daughter back, I know I can never have. The political resolutions just don't seem to me so important.

For Jim it's possibly a way of coping with the real forlorn horror of it all, all the loss. It's kept him going, kept him fully engaged in something he felt a driving need to do. I don't have that drive. What has kept me going is, at root, that not to have done so would have been worse; we have two surviving children who have futures and we have grandchildren. In the real raw grief of the time I had good friends and that kept me going too. I had support from friends who, when they saw me retreating – you lose confidence, the rug has been pulled away and you can't stand up for a while – they would not let me; they would come

and find me and take me out for the day and that was a help when I look back. It was the true mark of friendship to see that this was important.

Meeting with the other families was difficult but also quite enlightening. The good thing about a group like that is you don't need to explain to anyone, you know where you all are; you just reach out and give a hug. You can do something about most awful things but with death and loss there is nothing we can do and that is it, in a nutshell.



Julie Bailey is a founder member of the patient and family group Cure the NHS. She has been at the forefront of a public campaign for a full public inquiry into what went wrong at Stafford General Hospital where her mother, Bella, was one of many hundreds of elderly people who died, victims of failures in standards of care and leadership in the now infamous Mid-Staffordshire NHS Foundation Trust in the years 2005 to 2008.

I haven't grieved for my mother. I try not to think about her. She comes into my mind and I have to block the thoughts but it comes over me when I least expect it, when I am in bed in the middle of the night or dozing and I let my guard down. Then I am back on the ward with mum again. It's been five years but I just can't think of a moment when I've been happy since she died. It's the circumstances [of her death] and the guilt. I feel terribly guilty about what happened. We all do, the others [relatives] more so than me. They feel the guilt because they didn't know what was going on and allowed it to go on. My guilt is that I knew what was happening and I let it happen and didn't stop it there and then. I look at how strong I have become now and think if I had been stronger then I might have been able to do something about it. And perhaps Mum would have been alive today.

"I think if I stopped the grief would rush in. I will only be able to grieve for my mother when this is over."

I feel that it happened under my nose and I couldn't do anything about it and that I colluded with the staff. It feels worse because I made friends with them, I talked to them and tried to get favours that way, instead of challenging them. I took the route that I would go along with these people and make out I didn't know anything or see anything, but I lost mum anyway.

There were times when I didn't even believe my mum. She told me things at the beginning, in the first four days, and I thought she must have been hallucinating. There's that guilt.

I think the campaign helped because it allowed me to focus on something else. I would be in a very bad place now if I hadn't had the campaign. Something took over me when I lost Mum. I couldn't sit down. I couldn't keep still. I wasn't in a good place. I got home from losing Mum and I ran myself a bath and found myself just scrubbing and scrubbing until I bled. I could smell the hospital on me, all the dying, so I got out of the bath and just paced and paced. The following day the director of nursing pushed a letter through the door saying I should call her if I had any concerns. I was on the phone for 45 minutes begging her to help the other patients on the ward I had left behind. I was on the floor and I thought I could be crushed or I could get up and do something myself. That is when I went to my MP and the Health Scrutiny Committee.

It was anger. I had a mission for mum to uncover what had happened. I lost mum on 8th November and by 20th December the campaign had been launched and I started to receive letters from other people saying the same things had happened to their loved ones and I was out interviewing other people and I knew I had to be the strong one for all these people.

It's been five years, filled constantly with the campaign. We are a really close-knit group and that kept us going. We have never argued or fallen out. We have just put our heads down and gone for the same thing. This will only end when we get accountability and we are confident that other loved ones won't suffer like ours did.

I think if I stopped the grief would rush in. I will only be able to grieve for my mother when this is over. I think we have all put grieving on hold to focus on what is needed. It's important that other people don't have to feel the guilt we feel now and have these memories.

I do feel a little bit alone because I am the leader, I am the support for the group, so when I do break down I feel as if I shouldn't. It's too painful for them. I am their support and the leader.



Linda Hurcombe's daughter Caitlin took her own life in 1998. Caitlin wasn't depressed, Hurcombe says, but had asked her GP to prescribe her an SSRI antidepressant because she had heard that they helped you lose weight and feel great. Hurcombe says the

drug's side effects – emotional numbness combined with a gnawing restlessness, called akathisia – played a part in propelling a young woman with no previous suicidal tendencies to hang herself.

My prime motivation was to prevent it happening to other people. I don't want anyone else ever to feel like this.

I knew that nothing was going to help me but I decided I could use my skills, which are campaigning and writing, to make sure it never happened to anyone else. I would get the inevitable question from friends, 'Is this helping? Is this a catharsis for you?' and I was so offended. People said I was feeding my grief. The hardest thing for me was friends not accepting that, because something was useful to them, it could still be lethal. I have never said the pharmaceutical companies should withdraw the pills. I have just wanted them to be honest about their effects.

There was a point when it turned from an individual tragedy to an international iniquity. I would say I was galvanised. I went to the US to take part in a psychodrama weekend with parents with a similar loss, in Houston: 25 parents who had lost children after going on SSRIs – 16 children – and six of those children were called Caitlin. That was bizarre and uncanny.

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There is absolutely no doubt in the world that contact with other bereaved parents made all the difference. You are encouraged to feel you are mad, especially among friends who were using the medication I was talking about. There is this incredible sense that nobody else is like you, you are a mad, bereaved parent. They pat you on the head. I hadn't lost my intelligence, my sense of balance; I had lost my daughter. So meeting up with other parents was so affirmative, but at the same time overwhelmingly shocking that all these children took their lives in similar ways, having been prescribed SSRI antidepressants.

The campaign wasn't about anger. I would like to say it was objective. I was and remain interested in the science of the brain and benefits/risks of the medication and the politics of the pharmaceutical corporations. So if it was anger, it was a very intellectual form of anger.

I also set up Caitlin's Kickstart Award. It makes grants to young people to enable them to attend college. That has been a fabulous blessing. It's in its 12th year and we have given away about £30,000 to support students going into higher education. That is about continuity. Having been a tutor myself, I am very proud of that.

My view of life is that you carry with you all the events that have happened to you, not as a burden but like a river. I'm in a coracle, on a river. Putting things away in boxes, closing chapters, isn't for me. I sometimes wonder about people who choose that way of dealing with these tragedies – do they remember their dreams? Caitlin comes into my dreams. In my dreams all kinds of wonderful things happen – at which point it is waking up that is the problem. ■

Commentary, by Colin Murray Parkes

Colin Murray Parkes is a psychiatrist, Bereavement Care editor, and the author of numerous books and publications on grief. Catherine Jackson asked him what his experience had taught him about anger and campaigning after bereavement, and the following comments do not relate specifically to the cases above.

When someone dies, it's common for people to look for someone to blame. When something bad happens we think it is being done to us by some being, whether god or man. We ask 'Whose fault is it? Why me?' It's almost a reflex response and it's very prominent in times of grief and bereavement. When we are feeling the most enormous psychological pain we can ever experience, it's natural to think, 'Who did this?'. And some bereavements are culpable – murder, neglect – it's understandable that people will seize on that as something they have got to put right.

A lot of complaints are made against hospitals after someone has died. Some are deserved; others may be an expression of rage and anger that is more to do with grief than culpability. The people who deal with these complaints are aware of that. When I worked at the Royal London Hospital the complaints department would refer people to me and they would come expecting me to defend the hospital or to support or not support their case and they were surprised to find I was neutral. One woman, her sister died in hospital and her complaint hadn't been handled well. She had received a fair amount of defensive aggression; she'd been made to feel like an unreasonable child. Nobody really listened. She arrived to see me clutching the Ombudsman's letter [the adjudication in response to her complaint] – she hadn't been able to open it. It was causing her distress but she couldn't open it. So we talked through what it might say and she said 'But he might agree with me and that would be the end of the line – there would be nowhere else to go.' I think that was the point when she realised that really what she wanted was her sister back again. And she burst into tears. Then she opened the letter. Some of her complaints had been upheld while the ombudsman had been unable, on the evidence available, to support others. By this time, however, the complainant was ready to accept his judgment. Later she sent me a copy of the ombudsman's annual report in which he had used her case to argue for improvements in communicating information to both patients and families. She felt that she had been vindicated.

Perhaps this lady's reluctance to open the letter reflected her fear of grieving. She felt that if she started grieving she would lose her sister all over again. When she did start to grieve her anger diminished and she was able to get on with her life. She felt the hospital had been brought to book but also that she had over-reacted.

I think there is an element of denial here. The anger helps you avoid the grief – 'I am too busy and angry to grieve'. Anger can be an alternative to grieving: as long as we have this crusade, he lives on; I am keeping his memory alive by fighting for a cause.

But there are some crusades that really need to be fought. There were occasions when a complainant dropped a case and I rather wished they hadn't. They were drawing attention to a problem that probably ought to be put right and my therapy had reduced their anger so they didn't go ahead with it. I was not happy with that but it was their decision.

Guilt is also important. I have met many bereaved people who have been terribly guilt-ridden. One woman who came to me had been involved in a traffic accident and her mother had died. She was enormously angry and guilty. She had the feeling that somebody must be to blame. Eventually the inquest found that nobody was to blame. She wasn't happy with that; she had gone into the inquest hoping to have a culprit and she didn't get one. We talked about this in therapy. I was tempted to say: 'It was not your fault', but how could I know? What I actually said is, 'We all make mistakes. Anyone would feel dreadful if something like that happened, but is it something you should be persecuting yourself about for the rest of life as if you were the worst person in the world?'

I'm not too keen on labeling these kinds of behavior as 'pathological'. I don't use mental illness language very much. It's too easy to use that as a get-out. I see people as having problems, not diagnoses. In therapy you work with and try to help the person with the problem and that means not taking sides, being with them and helping them to understand themselves better and hoping that will do the trick, and sometimes it does.