

The Break Through Programme



Supporting Self - Supporting Others

The Break Through Programme is a self-management initiative set up to empower individuals affected by medical harm to work together in a supportive group context. The Programme is inspired by Josephine Ocloo, as a result of the untimely death of her daughter Krista which she believes occurred as a result of the medical negligence of a leading London hospital. The Break Through Planning team is made up of Josephine, as well as Louise Price and John McConnell and has been supported by AvMA as part of its support services.

Key Aims of The Programme

To enable individuals to:

Develop strategies for managing the negative emotional and psychological effects of medical harm;

Identify ways to move forward with their lives regardless of any action they might be taking, or thinking of taking, against a healthcare provider;

Meet other people in similar circumstances to gain support and develop strategies for self-empowerment.

The concept of the Break Through Programme came into being following the success of a one day event 'From Pain to Gain' which took place in May 2004 at Global Co operation House in London. This event was organised by what was to become the Breakthrough Planning Group and supported by AvMA and the Brahma Kumaris.

What was overwhelmingly clear throughout the course of this day and the feedback received from the evaluation of the event, was the need for a more in depth and ongoing programme of support to be developed for the future. Therefore in October 2005, a two day residential programme was held at Charney Manor Conference Centre near Wantage, Oxford, which was attended by twenty one people.

What follows is the collation of the material that came out of this programme - a combination of the participants experiences and their valuable contributions for an agenda for change -. This forms part of the research being carried out by Josephine Ocloo as part of her PhD on Medical Harm and Patient Empowerment within the NHS. The research design was constructed as a way of also enabling the

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programme participants to have a voice and tell their stories from their own perspectives.

The participants also wanted to see the development of a fully funded ongoing programme for the future.

Survivors of Medical Harm: These are our stories...

"We want our stories to be told with all the emotion and injustice as well"

Breakthrough participant

Ms A

She was treated by a private osteopath with his own practice, who was also a registered doctor with the GMC. She used private healthcare insurance whilst at work to pay for treatment. However, the osteopath gave her unnecessary treatment without providing any information or getting consent. He incorrectly administered an epidural into her lower back, with no monitoring equipment or qualified staff available. No monitoring was provided after the severe psychological reaction due to the physiological reaction of the epidural being injected inadvertently and incorrectly.

As a result of this situation Ms A has been diagnosed with Post-Traumatic Stress disorder and has continued to suffer with on-going severe mental health and physical problems. Her whole quality of life has also been affected, she lost her job because she could not cope with what had happened, it also affected

her relationships with friends and caused difficulties with intimate relationships.

Ms A successfully sued for negligence which took 6 years.

Agenda for Change

" The importance of the medical profession and systems for redress being more transparent, open and accountable in order to facilitate an individuals 'recovery' following an experience of medical harm "

Charlotte Swain

The medical harm relates to Charlotte's mother who died in hospital. Charlotte believes that her mother's drug administration in hospital and general medical care were mismanaged. The key concerns relate to the way that internal bleeding by Mrs Swain was dealt with as a result of the administration of strong pain-killers and how this was addressed once it was brought to the attention of ward staff by Charlotte's family. Other concerns about Mrs Swain's treatment related to a lack of general basic care. Mrs Swain had raised concerns about how she was being treated before her death and a failure to change her dressings. Mrs Swain's family were also upset that no post-mortem was carried out despite a request for one by the family and that eventually a false death certificate was issued relating to the cause of death. Charlotte feels terrible pain because her

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family 'entrusted our most treasured possession' to the Trust, who were then 'highly negligent causing suffering and terror to my mother'.

Charlotte also feels guilty that she didn't try to intervene more with the hospital staff to try and get something done, but she didn't want to make a fuss as she thought the staff knew what they were doing. At one point she felt that she didn't want to live, so was urgently referred for counselling by her GP. The family has instructed a solicitor to represent their interests at an inquest and written a letter of complaint to the hospital's chief executive and clinical governance team. After the inquest they are thinking of making a claim under the Human Rights Act - regarding Right to Life

Agenda for Change

"The importance of the Medical Profession admitting that they do not always get it right rather than covering up when errors, harm occurs"

Mrs Y

Mrs Y developed Post Traumatic Stress Disorder after the birth of her son. This illness also induced a host of other stress related illnesses. She was not treated for PTSD because of a refusal by the professionals treating her to acknowledge what had caused the illness in the first place. Eventually

the charity AIMS told her what was wrong and were willing to assist her to go to court but Mrs Y felt unable even to consider legal action because of how ill she was.

As a result of her situation Mrs Y lost her job through ill health. She was also unable to have anymore children and could not look after the one that she had. She says I was 'emotionally dead and unable to maintain relationships with friends as it took all of my energy just to stay alive. My body was ruined with the side-effects of the drugs I eventually had to take and none of them worked for the first four years anyway'.

Agenda for Change

"A need to change systems and the culture of the medical profession so that people can move on"

Stefanie Wywrot

Stefanie had a cataract operation on her right eye and the harm took place in the 3 month post-operative period. She was given eye-drops to use but because of inadequate advice about aftercare and no monitoring, she lost the sight in her right eye.

Stefanie is now registered blind, cannot go anywhere on her own and relies on others to help her. She lives on her own and has no family support. Losing her sight meant that she was unable to continue working as a machinist. She had her own business. She did attempt to sue for

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compensation, but felt that because she did not receive proper support from her solicitors, the case was dropped, but not before she had spent almost every penny that she had.

Her lack of income has also affected her relationships with family and friends. Her telephone was cut off because she could not afford it and because she is unable to write or read letters, she has become isolated.

Stephanie says 'I have been blinded as a result of the treatment I received. I will never come to terms with it and I feel bitter that no one has listened to my side of the story. My eyesight has gone forever; there is no treatment, cure or operation. I used to cry all the time, everyday I get depressed and worry how I am going to cope. I struggle with everyday life and with the knowledge that my sight will never return'.

Stephanie is interested in making contact with other people who have been affected in similar ways to herself by an adverse event. If you would like to make contact please get in touch with AvMA onwho will pass on your details?

Agenda for Change

"Treatment should not be withheld where corrective treatment is needed following medical harm"

Ms X

Ms X had an emergency caesarean section and was given inadequate

anaesthetic and so was awake during the surgical procedure. This led to pulmonary oedema, heart failure and the death of her daughter at 10 days old.

She has since been diagnosed with Post Traumatic Stress Disorder, Dilated Cardiomyopathy and depression.

Ms X said she feels 'emotionally crippled' by her experiences and physically hasn't felt very well since the break down of her relationship with the father of her child. She constantly re-lives the experience (she is sometimes immobilised with fear and experiences terrifying nightmares). She has been reliant on charities since the death of her child (which she says she holds the NHS responsible for) and the private counselling which she sought out, she says she found pointless.

She successfully took legal action proving she was given inadequate anaesthesia. She now says, 'I have no faith in the NHS and do not trust the institution at all'.

Agenda for Change

"Medical professionals need to be more questioning of colleagues practice"

Patricia Cooper

Mrs Cooper sustained her injury during surgery. Whilst having a hysterectomy, her bladder was damaged. This led to a number of other knock-on serious effects, which included the need for emergency surgery, and several

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further operations which often made the problems worse. She also developed peritonitis and other infections, developed a DVT, had to have her bladder rebuilt, her hernia repaired and her left kidney and gall bladder removed.

Mrs Cooper now has to self-catheterise four times a day, she also suffers occasional bladder infections and has limited walking and standing duration. She also has to rest for one hour each day in the afternoon. She can only drive for short distances with an automatic car with power steering. Her husband carries out all of the housework, ironing and shopping.

Financially she has had to stop her part-time job and has not been able to return to work. It has also cost a lot of money to have help in the home as they did not qualify for assistance and to pay for all the hospital visits to London.

She felt that she had coped well considering what she had been through, although she was angry at first, but now wanted to try and move forward. She felt however that the situation had been devastating for her relationship with her husband, but that they had come through it together. They both had counselling and her husband had a nervous breakdown. Although they successfully sued, it took 8 years and was settled out of court.

Agenda for Change

"The need for medical students to have a longer period being super-numery in order that that they have more time observing the practice of more experienced medics before being thrown in the deep end and learning on the job"

Helen Rowe

Helen's partner had not been feeling well and was losing weight. He thought he had worms. He went to see his GP who did not do any tests but told him to take an over the counter treatment. A week later he began to be sick, which happened up to 8 times and felt very weak. When he called the doctor he was told to rest, but then called the doctor later asking for a home visit. The doctor called and said he had a virus, which would clear up in a few days. Although he started to feel worse later, he believed he had a virus and did nothing more. He died alone the next day. It was later found by his doctor that he had died from a complication of unidentified diabetes. An independent expert found that the doctor had been negligent in three ways. Helen said, 'Adam and I were a strong couple, going through fertility treatment and moving home. This event has completely damaged my life in terms of relationships, children and future plans'. She also felt that her trust had been badly affected and she felt let down by the fact that she felt the GP's surgery knew after her partner died, that a diabetes related illness was involved, but that they had lied to her about this.

At the moment an inquest is taking place into her partner's death. She has also made a complaint to the primary care trust and the GMC. She felt it likely that following the inquest, she would be taking out a civil claim for negligence.

Effects of Medical Harm....

The pain of being labelled and not listened to: "They don't listen, don't want to listen"

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Effects of Medical Harm...

Being affected on many levels by the harm caused: physically, mentally, financially and in their wider relationships;

Shirley Johns

Mrs Johns was prescribed HRT with Thyroxine in 1994 for no proven reason. She was not given any warnings about this medication and no monitoring was carried out. Her health, described as 'excellent', after 30 years of taking thyroid replacement (100mcg thyroxine) then began to deteriorate. With the HRT she developed a number of adverse symptoms, blotches, a rash on her face, aches, pains, dry hair, sinus problems etc. Due to these symptoms in 1997 she made a request to her GP to stop taking HRT, which was then stopped suddenly without any monitoring. Her health continued to deteriorate. She requested tests which would show her ill-health was connected to thyroid dysfunction, but was told the test (TFT) was normal. She was then prescribed other medication which induced worse symptoms. Her health continued to deteriorate and she visited her GP a number of times and was given TFT tests that she was told were normal. Her GP appeared to ignore symptoms. In 1999, she was admitted to hospital for 3 days but was discharged without medical care. In 1999 she was again put back on HRT with Thyroxine. Eventually she went to a private hospital and was found to be folate deficient and the HRT was

stopped. In Oct 2000, after a long fight Mrs Johns found evidence of 'grossly abnormal TFT's' in her medical records and was informed she had a complaint.

She believes that she warned her doctors repeatedly of adverse effects, but no action was taken and that they continued to prescribe until it was too late, without any monitoring or following guidelines and procedures.

Mrs Johns says 'Let my horror story of taking HRT together with Thyroxine (unmonitored) be a warning to other women. It may not be so evident while HRT is being taken but after its sudden withdrawal from an unstable patient the results can be devastating. My health and life has been permanently changed for ever, the distressing painful symptoms persist although the thyroid function has been stable for almost two years. The burning of my face and mouth and aches and pains is almost unbearable and all would have been avoided if HRT had not been prescribed. I should have been stable for life taking 100 mcg of Thyroxine'.

Despite taking her complaint through the complaints system, taking legal action, going to the GMC and the Ombudsman's office Mrs Johns was unable to get any redress. Financially, she is thousands of pounds worse off because of private medical consultations, dental and legal fees. She believes the above mentioned systems do not work in the interests of patients who have been harmed and that there is no proper regulation of the medical profession. She believes that the

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GMC is well aware of malpractice among doctors and that the medical profession are not accountable for their actions or failures.

Effects of Medical Harm....

The whole family become victims not only the person who has suffered medical harm

Polly Fleet-Palmer

Polly Fleet - Palmer's daughter Rose was operated on at Harefield Hospital, now part of the Royal Brompton and Harefield NHS Trust, at the age of 8, having been born with a congenital heart defect. Mrs Fleet-Palmer and her husband were told that Rose needed corrective surgery. One doctor told them that the operation was routine, and another that it was complex but by no means unique. At no time were any risks of brain damage discussed with them and they consented to the operation. As a consequence of the operation, Rose suffered severe brain damage. No steps were taken to counter the neurological damage until the 8th post-operative day, although in the family's view this was evident from the third or fourth day. They believe that intervention could have taken place at this stage which may have minimised Rose's neurological damage. They first saw the surgeon on the 9th post-operative day, who claimed that nothing had gone wrong during Rose's surgery and that there was a definite chance of a full recovery. The family has never received an acceptable explanation

of what happened to cause the brain damage.

Rose is now registered blind, unable to speak, cannot feed herself and has cerebral palsy. She is entirely dependent and attends a school for the physically and mentally disabled. Her parents were unable to sustain legal action because their legal aid certificate was withdrawn on the basis that they were unlikely to win their case because of a similar case being dismissed by the courts. Missing medical records in their case also make it virtually impossible to prove exactly what happened to Rose. The emotional costs have been devastating for Mrs Fleet-Palmer and her family. She has suffered from depression, guilt and the pain of never knowing exactly what happened to Rose and why. She feels that there has been a cover-up and a lack of justice. The family also has to face the life-time responsibility of caring for Rose without much needed compensation and the battles which have continued for years, to secure for Rose the appropriate care that she needs and deserves from Social Services.

Effects of Medical Harm.....

Being labelled 'neurotic' and not believed when questioning or challenging the doctor about the treatment they have received, which has affected future access to appropriate healthcare.

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Denise Grimsdell

In 1996 Denise Grimsdell consulted her GP about a facial rash. The rash and other allergic and bowel symptoms including bleeding that emerged were mistreated, misdiagnosed, missed and were not represented in referral letters or were misrepresented in records. Her observation that she might have a mercury allergy after linking the onset of the rash to an amalgam filling, as well as a malabsorption problem, were discounted by her GP. Her observations were later proved correct by private tests and blood tests at the London Homeopathic Hospital, the latter also found antibodies relating to immune system inflammation that had been overlooked. By the summer of 1997, Denise felt so ill and weak; she was forced to give up sport, had lost a lot of weight and had developed intolerance to grains and other foods. This caused such strain with her employer that she left her job. The stress and misery of her situation caused her to start thinking about her abusive childhood and she was referred to a clinical psychologist for 'therapy' under an NHS Trust. In November 1997, the psychologist, without consent, applied hypnosis via a controversial induction. She was interrogated about her personal life and relationships, unethical suggestions were made and no respect was given for Denise's childhood, the person she was or the people she valued. Denise subsequently developed shingles and was later diagnosed with Post Traumatic Stress Disorder.

Denise's husband then made a complaint on her behalf. This was denied by the psychologist, whom the family maintain, falsified her records to cover-up the fact that she had used hypnosis. The complaint was then referred to the Health Service Ombudsman (HSO). The Ombudsman's office refused to investigate until threatened with legal action. As a result of this action they found that the family's complaint to the Trust had been mishandled, although they still failed to investigate the substance of the complaint. The HSO also refused to reimburse the family for the £7,000 in legal costs they were forced to incur. As a result of her experiences Denise has been left with the feeling that 'there is bias, dishonesty, complacency, secrecy and vindictiveness surrounding medical harm'. This she says 'disgusts my sense of morality and fair play. The strain of pursuing the truth, of injustice, of character assassination without a right of reply, of callousness in the face of the trauma caused, has damaged our lives and it hurts and is impossible to forget. I think it will always hurt and will never be forgotten. We do not consult UK doctors now.

Instead we consult complementary practitioners, who frankly have done a fantastic job in cleaning up the mess made of me by the medical profession'.

Effects of Medical Harm....

The enormous anger at struggling to find the truth;

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David Giles

In 1993 David who has suffered with epilepsy since childhood, experienced a seizure and was admitted to a hospital in Hampshire. David was taking an anti convulsant, which he felt needed to have the dosage increased in order to stabilise his fits. However, rather than doing this, he was changed to three different drugs which resulted in him experiencing adverse affects. After 8 weeks these drugs were stopped and changed back to the original medication.

As a result of his situation, David has continued to experience long term effects both physically and financially. He does not feel that he has obtained justice for what has happened to him.

Effects of Medical Harm....

The abuse of trust that can make you no longer want to use the health service.

John Willetts

In 1970 John became a blood donor aged 18, the youngest age you are allowed to give blood and continued donating for 25 years until he was 43 years old. In Feb 1991 John was told about a new way to donate blood so he changed to this new method. This meant that he could donate more frequently, without becoming anaemic and he could increase the benefits to sick patients by donating both blood plasma and platelets in one sitting. In 1994, John became the first person in Birmingham to pioneer another blood donation method, by agreeing to give blood in

a more concentrated form. This method allowed twice as much blood to be taken than previously, to gain more platelets than plasma whilst using fewer donors. This way of donating was particularly beneficial for sick patients because it allowing them to receive more blood from one donor, thereby reducing the chances of cross-infection. However within six months of using this method, John's health changed dramatically and over a period of years he went from someone who as a life-long non-smoker and drinker had been completely healthy, to developing a number of adverse symptoms. These included developing tinnitus in 1995, diabetes in 2001, receiving medication for hypertension and raised cholesterol in 2002, being diagnosed with prostate enlargement and a raised PSA in 2004, Dry Eye Syndrome in 2005 and developing a degenerative spine condition. In response to these developments, John found his own doctors to be 'passive and unresponsive'. In 1997 he went to a homeopathic centre who found a number of serious problems with his health which then prompted him to consult a solicitor for medical negligence. Yet despite being granted legal aid, two unsupportive expert witness reports led to the closure of his case in 1999. In response to his situation, John says 'I have learned to live with these conditions for more than ten years. You learn a lot about coping strategies especially on your own'. He has had no recourse to public support, sick pay or social security,

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but as he runs his own business he feels his physical conditions will soon force him to look for alternative work. Ultimately John says 'If I had my life all over again, I would still be a blood donor to help benefit others'.

Healing the Pain

The need to deal with the anger in order to move forward;

Realising the impact of the harm upon personal relationships;

The need to stop trying to run away from what has happened and to take ownership or accept what has taken place;

Recognising when you need help;

Courage - becoming stronger -
Affirming that you have 'come through it' 'Coming back'

Strategies for Self-Empowerment

Changing the system;

Continue to challenge inappropriate care and questioning things more as a recipient of healthcare;

Drawing on previous professional skills;

Drawing on professional support from family and friends and those who understand;

Preparation;

Develop knowledge in order to feel confident about questioning;

Become more informed.

Being more challenging -

A Time for Justice

Medical Harm: The Facts:

885,832 patient safety incidents (PSI'S) were recorded in a survey of 256 NHS acute, ambulance and mental health trusts in 2003-04 and in a follow-up survey in 2004-05, around 974,00 PSI's were reported. Hospital acquired infections were estimated to increase PSI figures by around 300,000 incidents.

It is estimated that about 50% of these incidents are preventable.

National Audit Office 2005:1)

No actual data is available on the numbers of negligent PSI's. Respected international studies (The Harvard Study 1991; The Quality in Australian Health Care Study 1995) found between 27-51% of PSI'S in the studies were negligent. Extrapolated to the NHS, this may mean that a quarter of PSI's (243, 000) occurring in England may be negligent. Yet in 2004-5, there were only 5,609 legal claims for clinical negligence (National Health Service Litigation Authority (NHSLA) Website 31-1-06), making up only 2% of possible claims.