

ACTION ON MEDICAL NEGLIGENCE ASSOCIATION

Campaigning for Victims of Medical Crime and Negligence

FURTHER SUBMISSION

TO

NORTHERN IRELAND HUMAN RIGHTS COMMISSION

29111/2001

We thought we had made a strong case for inclusion of a disclosure clause in our proposed bill of rights. The cases you saw perfectly illustrated that failure to disclose the details of a medical mishap can result in death and further serious injury. If saving people from being crippled or dying is not a suitable objective of a bill of rights then nothing is.

Our members think it would be a serious omission to ignore aspects of healthcare and human rights which ordinary members of the public would consider the most basic of all rights. In a recent Belfast Telegraph poll a massive 49% identified healthcare as the single most important issue, which politicians in our Assembly should address.

We do appreciate that our proposals raise some legal issues, which the medical profession no doubt have reminded you about. We appreciate that medical professionals have a perfect right to defend themselves, but not to sacrifice patients in the process.

Our ongoing Organ Retention Enquiry highlights the need for new guidelines and legislation on the whole principle of consent. Whilst there may be little argument about the principle of informed consent in theory, there are of course enormous complications in practice.

We enclose as part of this further submission a discussion document for a meeting last May. This document presents you with alternatives and general fallback proposals to those in our submission document.

THE GENERAL DISCLOSURE CLAUSE is similar to one proposed by your working group but omitted from your Consultation Document. This general disclosure clause would of course not only reduce suffering and death arising in medical negligence but also have implications in many other areas e.g. failure to make early disclosure in the case of BSE related CJD risks or non disclosure by the nuclear industry e.g. Sellafield, or the sorry situation of farmers deceived by MAFF over the hazards of organophosphates in sheep dip or the failure of the M.O.D to initiate an intensive detoxification programme for Gulf War veterans. Would you at least give serious consideration to a general clause?

We are disappointed that you have not as yet referred our concerns to your Research and Investigations committee and you also appear to have abandoned any intention of looking at individual cases.

We do hope all our efforts have not been entirely in vain!

N.I.H.R.C MEETING

WEDNESDAY 2ND MAY 2001-04-23

STRATEGY POINTERS

We are well aware that some human rights abuses, we have identified, may have relevance and application outside the specific area of medical negligence and we have no **difficulty** with these being dealt with in an all-embracing manner. Examples include harassment and personal records.

CODE OF SILENCE AND DISCLOSURE CLAUSE

The code of silence enshrined in the Hippocratic oath, in effect negates the purpose of the oath i.e. protecting the patient. We do realise that, for many doctors, it does present a serious dilemma, since it forces them to adopt a position and behave in a fashion, which is quite contrary to their instincts and training, in denying health care and betraying the trust of the patient. It is of course a very strong code and woe betide any doctor who breaks it – as perfectly demonstrated by the whistle-blower anaesthetist in the Bristol Royal Infirmary scandal, whose brave stance was rewarded by being forced to emigrate to Australia to **find** employment.

We detect a groundswell of opinion for its removal and that would be a step in the right direction. However its removal would help, but not completely protect the right of medical negligence victim, since medical professionals would continue to defend themselves by any means at their disposal. We would still require a disclosure clause. As with most human rights issues there is a conflict of rights, but obviously the life, health and well being of patients takes precedence over the legal rights of medical professionals. A disclosure clause could be specific (our preferred option) or general.

SPECIFIC: Medical professionals are obliged, without prejudice to their legal rights, to make a full and immediate disclosure of a medical mishap, in order to preserve the life and protect the future health and well-being and other human rights of the patient.

GENERAL: “employees, agents or official of a state body are obliged to make immediate disclosure of information whose concealment poses a threat to the health and well-being of any citizen of the state”

INFORMED CONSENT

The original purpose of medical consent was of course to protect the medical professional against a charge of assault – since medical professionals are the only people (apart from defence forces) who can legally attack someone with a knife. We want a consent, which also protects the rights of the patient.

A general right to consultation and consent is of no use. It needs to be stated in precise terms as we have suggested, and it needs teeth in the shape of legal and disciplinary measures, if it is ignored or breached. In legal terms does contract law apply to medical consent?

{Note debate on B.M.J. **website** April 2001)

ACCESS TO HEALTH CARE

A general “right of access to health care” is too vague. It needs to be couched in more specific terms, for example “A right to open and equal access to honest, safe, and appropriate health care” which would cover many of the areas of bad practice and discrimination highlighted in our submission.

DISCRIMINATION

We want anti-discrimination clauses to recognise and give specific mention to medical negligence victims as a marginalised group (or in general terms to persons in dispute with a state agency). We feel that even if we have disclosure, consent and access clauses to our satisfaction there will remain a hostile attitude towards medical negligence victims, affecting the care and support they receive from health, social educational and other state services.

NEW INSTITUTIONS

We suggest the setting up of new institutions within Northern Ireland, to deal with the issues we have identified. Two points on this

1. We do not believe there are any legal/ constitutional obstacles to such institutions under the terms of our devolved administration- but perhaps we need an opinion on this.

2. How would such institutions complicate working relations within the U.K or health provision cooperation (e.g. in border regions) with the Irish Republic (which already has a very different system)?

HEALTH INSPECTORATE/OFDOC/HEALTH SERVICES AGENCY

This is an important objective. In response to the Nottingham disaster, a National Patient Safety Agency is now being set up- to add to all the other bureaucratic bodies – established in the last two years. This is a further example of a “bitty”, uncoordinated approach, which won’t work and which has more to do with the appearance, rather than the substance of things (as with much else these days)

We want a strong, independent powerful body, call it what you will – to oversee and advise on all aspects of the delivery of health care in Northern Ireland. We want this body to have strong investigative and disciplinary powers to effectively deal with poor practice, incompetence and negligence. Under its umbrella could be

A) A task force targeting medical negligence- we have TSN and TFP why not TMN? This body could be headed up by a risk management consultant (possibly from another high risk industry e.g. Civil Aviation) and involve itself in

- ⚡ Operating a mandatory monitoring and data-gathering unit.
- ⚡ Developing and enforcing risk management strategies.

Inspecting the performance of medical professionals, GP practices and hospitals.

- B) A COMPLAINTS BUREAU handling all cases where malpractice or medical negligence is disputed and disclosure has not been made. The first priority of such a body is to ensure that damaged victims are not denied access to the best possible health care. (Our present complaints procedure could still be used **to handle** complaints of a less serious nature e.g. waiting times or a doctor's manner etc.)
- C) AN **ARBITRATION** TRIBUNAL Coupled with a personal injury compensation agency to quickly deal with cases where the victim cant or does not want to pursue legal action.

EMERGENCY UNIT

Since putting in place all of this will take some time, our members want the setting up of a small unit to address their immediate concerns, stop their ongoing abuse and obtain for them, honest, appropriate health care, i.e. diagnosis/prognosis and the best available treatment. In some cases we propose funding for members to obtain private treatment outside Northern Ireland or the U.K. We are prepared to liase with such a unit, which should be set up without delay as a short-term strategy.

LEGAL OPINIONS

- We would like **N.I.H.R.C** to fund legal opinions on
- Psychological LABELLING with particular reference to Libel Legislation and the Right To A Fair Trial.
 - MEDICAL RECORDS and patient property rights and again implications for a fair trial.
 - The whole issue of INFORMED CONSENT

CRIMINAL TEST CASES

We would like to run several test criminal cases involving

- Dangerous inappropriate treatments especially SECOND OPERATIONS
- Removal of HEALTHY ORGANS
- HARRASMENT whose main purpose is to force people to drop a legal case or accept an early low settlement.

Can **N.I.H.R.C** help in this area?

INOUEST SYSTEM

There is universal dissatisfaction with our current inept and inadequate system for dealing with untimely and violent deaths. It is of course an issue which should have been addressed years ago and, but for the complications, produced by our troubles, this would have happened.

In new arrangements we want specific mention of procedures and guidelines in cases of untimely death under medical care. A small interested group of our members could be formed to engage with **N.I.H.R.C** and other interested parties on this specific issue.

PRIMARY OBJECTIVE

FOR

A BILL OF RIGHTS

IN

NORTHERN IRELAND

Our primary objective is a clause in our proposed Bill of Rights, along the following lines:-

“MEDICAL PROFESSIONALS ARE COMPELLED, UNDER LAW TO MAKE FULL AND IMMEDIATE DISCLOSURE OF A MEDICAL MISHAP.”

We shall endeavour in this submission to make a case for such a clause.

- A. It is essential in some cases to save the life of the victim e.g. where a drug overdose has been administered or where a colonoscopy has caused a tear in a patients colon.
- B. It is necessary in order to ensure that victims receive urgent remedial health care, in order to ameliorate, if possible, the long-term effects of the disaster.
- C. It is a vital clause in order to prevent the chain of human rights abuses which inevitably follow a medical mishap, and which cause enormous stress and frustration for the victim.
- D. In some cases, it is the only way to avoid a situation where victims are subjected, for whatever reason, to further inappropriate treatment and surgery.

Introduction

The Action on Medical Negligence Association is an entirely voluntary and obviously cross -community group whose only agenda is

- a) Pressing for measures to reduce the carnage
- b) Campaigning to protect and defend the human rights of all victims of medical crime and negligence.

Our remit includes not only the N.H.S, but also all private and complimentary health care areas. We are not engaged in a “witch hunt” against medical professionals but rather in changing attitudes and systems which give rise to incompetence and negligence and within which rogue and incompetent medical professionals can thrive. We do not exclude any areas which impinge on the health of people in Northern Ireland , including all areas of public health and safety We particularly welcome the formation of a Food Safety Agency freed from industry control although it is a pity we didn’t see fit to do the same for Medicines and Drugs Control (15 out of 36 members of The Committee on the Safety of Medicines have industry links). Northern Ireland is in the literal (and metaphorical) sense a very “sick” society with one of the worst health records in Europe, and we welcome all the initiatives, for example, Promoting a Healthy Active Life Style, Targeting Social Need or Tackling Fuel Poverty which make a difference. However, on many aspects of the “Social Theory” of Preventative Medicine, the jury is still out.

MEDICAL NEGLIGENCE A PUBLIC HEALTH AND SAFETY ISSUE

It is a supreme irony that, from a Public Health and Safety perspective, the practice of medicine is in itself a major threat. This is conveniently ignored in “Investing for Health” (November 2000), which mentions practically every other threat to the health of our people, despite a government report which states that “10% of patients entering our hospitals suffer an adverse event”! In the absence of official statistics, (N.I. hospitals don’t even issue mortality figures) we have to rely on our own figures and the conclusions of research projects in the past five years. Remarkably, these all come to approximately the same conclusions. *

Every year in Northern Ireland, there are about 5,500 medical mishaps. In around 1,000 instances the mishap contributes, in whole or part, to death. Deaths from medical ‘accidents’ therefore equal deaths from all other ‘accidental’ causes including road, fire, water, domestic, workplace, leisure, suicide, hypothermia and all other “violent deaths”. Of this 1000, approximately 100 die from contracting an infection e.g. MRSA whilst in hospital. After heart disease and cancer, ‘medical mishaps’ comes third as the cause of an untimely death in Northern Ireland.!

Every year, a further 4,500 suffer from a medical “accident” whilst under health care. For 4,000 of these the effect is minor and /or short term, but for about 500 the outcome is quite serious ranging from moderate to severe damage and for about 30 - 40 patients each year the outcome is quite catastrophic.

In conclusion, we are dealing with a very serious issue and one which has, statistically, touched the lives of more people in Northern Ireland than our ‘Troubles’. Victims of medical crime and negligence far outnumber victims of our Troubles. We therefore make no apologies for raising the profile of this issue, which involves a host of human rights abuses. The vast bulk of our membership are angry and depressed to realise that they would now be better off if they had received no medical treatment (and some members’ relatives would be alive). Indeed a **sizeable** percentage would now be in robust good health.

*“The most recent research, by University College London researchers, to be published in March 2001 issue of the British Medical Journal

PROSPECTS FOR CHANGE

It is a matter of great concern to us that there appears to be no will on the part of the people in charge to seriously address measures to reduce the incidence of adverse events, despite the fact that many experts agree that the introduction of:-

- ⊖ MONITORING of not only all mishaps but also near misses,
- ⊖ the introduction of SAFETY CHECKS and FAIL SAFE SYSTEMS
- the rigid enforcement of RISK MANAGEMENT STRATEGIES
- ⊖ an EFFECTIVE DISCIPLINARY SYSTEM to deal with medical crime, error and incompetence

would, at no great extra cost, reduce the incidence of medical disasters by 70% over two years and by 90% over six years.

Why can't we deal with medical "accidents" in the same way we deal with Road **Traffic** Accidents i.e. we gather detailed statistics on why, how and where accidents occur and, on the basis of these statistics, develop strategies in terms of safer cars, safer roads, targeting drink/drug driving, speeding, and recklessness and eliminating accident black-spots?

Medicine is a high risk business. So why not borrow techniques from other high risk industries e.g. Civil Aviation? If our N.H.S. were a civilian airline it would be grounded!

There appears to be NO LEARNING CURVE in tackling medical disasters. Our membership is largely divided into groups of people who have been damaged in almost precisely the same way and it is distressing to us that these groups are being constantly added to. The recent tragedy **in Nottingham** where a toxic cancer drug was injected into the spine rather than a vein perfectly illustrates this. Early in 2000, a Channel 4 series of programmes called "WHY DOCTORS MAKE MISTAKES" identified 13 cases where this precise accident happened. Was no-one paying attention?

(We are currently **in** the process of putting together a RISK MANAGEMENT STRATEGY DOCUMENT)

MODERN MEDICINE

Medicine has made enormous progress over the last 100 years and particularly from 1945 to 1985, in areas such as mass vaccination, antibiotics, cancer care, transplant surgery and orthopaedic intervention e.g. hip replacement. However this very progress has been bought at a price in terms of increasing numbers of medical disasters.

INTRODUCTION of NEW TECHNIQUES, THERAPIES and MEDICINES often industry-driven, is in itself a problem, especially if there are inadequate clinical trials and their introduction is neither monitored nor effectively controlled. Past examples include OIL BASED MYLIN DYE injected into the spine to enhance X-rays, which crippled some 4,700 people across the U.K (some 90 in N. Ireland) in the late 60s and early 70s. {Although banned in 1976, we have come across victims who had it injected into their spines in the 1980s) and of course THALIDOMIDE which produced 25 damaged babies in N. Ireland and whose clinical trials were forged. The fact that many other countries never licensed either of these highlights our inadequate controls, and in the continued absence of an adequate Medicines Control Agency, the possibilities for future disasters exist. We are currently concerned about the damage being done by EPIDURALS/ SPINAL ANAESTHETICS and the absence of proper LICENCING OF SURGERY, allows inexperienced surgeons for example “have a go” at KEYHOLE SURGERY with frequent disastrous consequences.

INCREASING COMPLEXITY:- complexity coupled with rapid change is also a factor in medical disasters. The more complex it becomes the more opportunities exist for disaster, and an increasing number of doctors may find themselves ‘out of their depth’. B.M.A figures suggest an incompetence level of 13%. Of course incompetence is a relative term ▪ many attempt to perform above their level of competence.

MORE INTERVENTIONALIST AND INVASIVE ▪ much unnecessary invasive testing and investigations, which often contribute little to diagnosis or treatment, are taking place and there has been a dramatic increase in some forms of surgery e.g. spinal surgery and caesarean sections.

LOST “ART” OF DIAGNOSIS ▪ over-reliance on technology instead of LISTENING TO PATIENT, TAKING MEDICAL HISTORY etc. .contributes to many cases of misdiagnosis and inappropriate treatment. SPEED and WORK-STRESS is a factor.

INCREASED SPECIALIZATION is also a consideration. Doctors tend to know ‘more and more about less and less’ and in this situation find it difficult to deal with the whole patient.

RAISED PATIENT EXPECTATIONS ▪ the perception that there are no limits to what modern medicine can achieve has produced an insatiable demand for treatments which may be ill-advised and often counterproductive. Perhaps we should all expect less and recognise the limitations and human frailties of medical professionals.

In conclusion, we would advocate a more conservative and cautious approach.

MEDICAL ETHICS

There is very little evidence that ethics play much of a part in the practice of modern medicine. Basic tenets of Hippocrates are ignored -

- ≈ PRIMUM NON DOCERE (above all do no harm)
- ≈≈ TREAT THE WHOLE PATIENT
- . SOMETIMES THE BEST THING TO DO IS NOTHING
- . DON'T UNDERESTIMATE THE NATURAL HEALING POWER OF THE HUMAN BODY
- ≈ SHOW RESPECT FOR THE PATIENT

The only advice they really seem to have taken on board is not to squeal on colleagues. This Mafia-like code of silence or “omerta” poses a real problem for medical negligence victims.

Attitudes towards patients are still Victorian; patients talk about doctors referring to them in the third person as “**him**” or “**her**” or even “**it**”, as if they weren't there and as if their treatment had nothing to do with them. (Sir Lancelot **Spratt** lives!) Let us hope that the latest buzz word “empowerment” really means that and that patients will be communicated with, kept informed and involved in **all** aspects of their care and treatment, and that “informed consent” is adhered to. Obviously all patients should be treated with RESPECT, and in this regard we have concerns about the treatment of the TERMINALLY ILL, WOMEN, the ELDERLY, MENTAL HEALTH PATIENTS, AND PATIENTS WITH EMBARRASSING ILLNESSES.

DIGNITY OF THE DEAD OR HUMAN REMAINS should also be respected. This has been highlighted by recent scandals e.g. ORGAN RETENTION, POST-MORTEM, or bodies left lying on a chapel floor. However, it is curious that our society seems to have no problem over the undignified disposal of aborted fetuses or the dissection of unborn living embryos, which we would also like to see treated with dignity. Should we have a criminal charge as they do in other countries e.g. Canada of “IMPROPERLY OFFERING INDIGNITY TO HUMAN REMAINS”?

In general the incredible **arrogance** and **paternalism**, displayed by some medical professionals, is conducive to a climate of disrespect and lack of care and is a major factor in **medical** disasters.

However in the AFTERMATH of a MEDICAL MISHAP any pretence of medical ethics is completely abandoned and the unfortunate victim or relative is treated in a highly discourteous uncaring cynical and even brutal fashion, which anyone who hasn't experienced it would find quite incredible. Whatever may be said about the original ‘mishap’ it was probably not deliberate but what follows a ‘mishap’ is quite deliberate and obviously CONTRARY TO MEDICAL ETHICS. This cynical attitude is perfectly illustrated in the language used by Medical Defence Bodies. An annual report, for example, states:

“We are pleased to report a reduced number of ‘hits’ in the last financial year”

Not much sympathy there for the unfortunate victims! Neither is there a mention of tactics to reduce the number of ‘hits’; by pushing for change as for example, the Motor Insurance Industry has done.

POST DISASTER

In the aftermath of a medical disaster the unfortunate victim ceases to be a patient in urgent need of help but rather the enemy, the adversary in a potential legal case someone who can claim compensation, damage the reputation of medical professionals and the reputation of the hospital.

Research and membership surveys suggests that what aggrieved patients really want is

- . EXPLANATION ▪ the truth about what happened and why.
- ⌘ ADMISSION ▪ an acknowledgement that a mistake has been made
- ⌘ PREVENTION ▪ reassurance that lessons have been learned and the error will not be repeated.
- ⌘ APOLOGY ▪ when something has gone wrong, someone should say sorry
- COMPENSATION ▪ the last thing on their mind ▪ but obviously they eventually seek financial help to carry on their lives and support dependants and **carers**.

The following is a TYPICAL SEQUENCE of EVENTS following a disaster in a **hospital**:-

- ⌘ AVOIDANCE by STAFF ▪ even their doctor / surgeon may fail to talk to them.
- ⌘ EARLY RELEASE ▪ the victim is often ejected **from** the hospital with unseemly haste ▪ sometimes three or four days after major surgery.
- ⌘ NO REVIEW ▪ of their case at hospital outpatients
- ⌘ NO G.P. HOME VISITS ▪ G. P. may refuse or send a **locum** / another doctor
- ⌘ COMPLAINTS ABOUT OUTCOME IGNORED ▪ victims put off by references to “post operative debility” or “you have to expect some problems / pain after major surgery”
- REFERRAL BACK TO DOCTOR/ SURGEON DENIED.
- ⌘ FORCED RETURN TO WORK / SCHOOL- visit from or referral to Board Doctor often five/six weeks after major surgery, which, even if successful, would require a longer recuperative period. In a fear of losing benefits or job, many victims struggle back to work but are usually unable to sustain it. (An early return to work is later used against victims in a complaint or legal process)

Damaged children of school age visited by E.W.O - parents threatened with court action. General Practitioners though obviously in possession of the facts of the disaster, may now write notes referring to “post-operative debility and Depression”

- ⌘ PATIENT REALISES DAMAGE/DISABILITY PERMANENT- Pain/Symptoms not easing or perhaps getting worse.
- ⌘ DEMAND FOR REFERRAL TO ANOTHER CONSULTANT - which may take some time and, even when it happens, will produce nothing (consultants in N. Ireland form very tight knit groups which will not break ranks) A typical scenario would be a victim finally, after a year or more getting an appointment with a different consultant. He or she has an appointment at, say 10am, but at 1pm are still waiting in a now empty waiting room. When ushered into the consultant’s room, he or she finds that the Consultant has gone and they are being dealt with by a very defensive junior doctor. Members speak about total discourtesy and even doctors/nurses etc. laughing at their predicament.
- ⌘ PATIENT FACED WITH EMPLOYMENT CONSEQUENCES- difficulty with employer, who may demand medical notes / threaten employment and pension rights etc.
- ⌘ DIFFICULTIES WITH SOCIAL SERVICES-Since officially the operation/procedure has been successful and nothing in medical notes indicates otherwise, there may be serious difficulties obtaining sickness benefit/ incapacity/disability living allowance. Members speak of OPEN HOSTILITY, not only from health but social services.
- ⌘ LABELLING ▪ INVENTION OF PSYCHOLOGICAL DISORDERS- at some point terms such as “disgruntled”, “vexations”, “neurotic”, “functional overlay”, personality disorder”, “referral for psychoanalysis” or even “psychotic” or “schizophrenic” start appearing in notes. The obvious purpose of this is to
 - a) Confuse the issue
 - b) Discredit the victimand in following complaints/legal procedures will be used against them.
- ⌘ FAMILY/MARITAL DIFICULTIES- the physical pain/disability, frustration and financial consequences start having a serious effect on family/marital relationships; carer/partner may start believing hints of “its all in their mind”.
- ⌘ COMPLAINTS PROCEDURE- not realising that they are complaining to potential defendants in a legal case and that complaints managers see themselves as part of the legal defence team, victims get involved in a frustrating, tedious and protracted correspondence, in the hope of getting treatment and answers. Since this is rather like asking a person, who has been mugged in the street, to complain to the local crime syndicate, it is patently ridiculous and we advise members to, by all means register a formal complaint, but NOT TO GET INVOLVED in a complaints procedure, which for medical negligence victims does not work (we know of only one person, who, after waiving rights to compensation, successfully pursued a complaint).
- ⌘ REFERRAL BY HEALTH BOARDS ▪ victims demanding and getting independent referrals, may find themselves travelling to other parts of the U.K for referrals, which turn out to be totally dishonest and deceitful. (Boards should be condemned for wasting N.H.S funds in this way)

⌘ LEGAL ACTION -by this stage, at least a year has passed and victims or families may consider taking legal action. Unless they are totally destitute, they will not get full legal aid and unless they have substantial financial resources, that may be the end of it. (In a recent case a man sold his house and car to fund a case-few have that kind of courage! Despite spending £1.6 million defending itself, the hospital lost and paid out £400,000. The man afterwards admitted he would have been happy with an apology and £250,000!). Some lawyers take the view, that the best use of available resources may be to go to a private specialist unit outside of the U.K for diagnosis/prognosis and if possible treatment, and a number of members have taken that route. MOST MEMBERS ARE DENIED ACCESS TO THE LAW “No win, no fee” is not available in Northern Ireland and the insurance option is limited and getting more expensive, Our statistics show that less than 2 % of victims win compensation. If victims do not have funds or do not win an often protracted legal case they may be

a) Denied all knowledge of their physical condition or how it is likely to progress, i.e. DIAGNOSIS/PROGNOSIS

b) Denied all forms of treatment, even palliative care.

In all of this we have to appreciate the unequal struggle between a well-funded insured medical defence system and a severely damaged and distressed individual, who may lack the physical and mental stamina to pursue a long tedious legal action.

⌘ INTERFERENCE WITH MEDICAL RECORDS ▪ the destruction, alteration or additions to medical records is very common. In cases, where we have asked the R.U.C to intervene and investigate such activities the stock response has been “these are the property of the G.P, Hospital Trust, etc.” with the inference that they can treat their property how they please. We would argue that patients have PROPERTY RIGHTS on their records, in the letter and spirit of FREEDOM OF INFORMATION and DATA PROTECTION LEGISLATION and that tampering with their records is clearly a CRIMINAL OFFENCE. (Despite enquires it is difficult to ascertain who has responsibility regarding the safe keeping of medical records- C.S.A or G.P Services Board Doctors or Medical Record Executives?)

⌘ HARRASSMENT ▪ Many members refer to being subjected to harassment when they threaten or commence legal action. We find it very disturbing that much of this is obviously sanctioned at an official level It includes

1. Malicious, abusive and threatening phone calls
2. Unsolicited delivery of goods and services
3. Invasion of privacy through surveillance and the use of concealed film cameras.
4. In a few cases, breaking and entering of property

⌘ In some cases harassment encompasses the victims extended family. Laws on privacy and harassment are extraordinarily weak and need **strengthening** .

⌘ FURTHER LOSS OF HEALTH CARE RIGHTS- e.g. difficulties obtaining the services of a GP or denial of treatment for further unrelated ailments or accidents .

- ⚡ ORIGINAL AILMENT UNADDRESSED - in all this nightmare scenario, the most disadvantaged victim is the one who has experienced a complete MIS-DIAGNOSIS who ends up with perhaps two problems instead of one and whose original problem may never be dealt with.
- ⚡ FURTHER INAPPROPRIATE TREATMENT/SURGERY- we view with very grave concern the situation where victims are subjected to inappropriate investigations, treatment and surgery and we have little doubt that this is, in many cases, clearly CRIMINAL in nature. Examples include victims, who never had a kidney problem, being subjected to further kidney operations, including in several cases, the removal of a perfectly healthy kidney” or victims, whose problem never was lumber, being subjected to further inappropriate lumber operations. We conjecture that the purpose of all this may be

1. To destroy or confuse the evidence.
2. To “noble” a victim, seen as a threat

- ⚡ FATALITY- where a death occurs there is obviously variations in the sequence of events described above. A surprising percentage of deaths, in medical care arising from a “mishap”, go entirely unnoticed by relatives, since doctors and hospitals are extremely good at explaining the sudden death of someone whose life did not appear in any danger. This is particularly true where the deceased is past middle age. Relatives of deceased victims speak of the frustration and anger they experience in trying to get answers even when compensation is not a consideration e.g. in the deaths of infants or the elderly. In their distress, relatives often fail to insist on certain procedures e.g. independent pathologist’s report. We are obviously very unhappy about procedures taken in the case of a sudden untimely death in medical care. Police are rarely involved and hospitals are allowed to conduct their own autopsy; no inquest may take place and even when it does, it is very unsatisfactory, in not establishing cause of death and not allowing questions **from** relatives or their legal representatives. Next of kin speak of having “insult heaped upon injury” and may have to relive the event over and over again, not being able to put their grief behind them until the whole affair is over; in cases, where a legal claim for compensation is made, this may take many years.

In conclusion the medical negligence victim faces a NIGHTMARE SCENARIO following the disaster. He / she is not only DOUBLY DISADVANTAGED but is subjected to enormous stress and frustration and has to endure a host of human rights abuses. There is ONLY ONE WAY to avoid all this, to deal with this ‘CATCH 22’ situation and that is very simple.

THE INCLUSION IN A BILL OF RIGHTS OF A CLAUSE MAKING IT ILLEGAL / CRIMINAL FOR MEDICAL PROFESSIONALS TO FAIL TO MAKE A FULL DISCLOSURE OF ALL FACTS RELATING TO INAPPROPRIATE OR BOTCHED TREATMENTS AND PROCEDURES - “WITHOUT PREJUDICE TO THEIR LEGAL RIGHTS”

THIS IS OUR FUNDAMENTAL OBJECTIVE.

VULNERABLE GROUPS

WOMEN

Women are three times more likely than men to suffer medical negligence. We are very concerned about the treatment of women by a male-dominated profession where some 95% of consultants are men. In four recent high profile medical scandals all the victims were female. Our largest group of victims are women who suffered horribly in botched hysterectomies. Other groups e.g. our **epidural/spinal** anaesthetic group are also all female.

Members speak of their gynaecologists as “brutes” and would like psychological profiling of all prospective gynaecologists to eliminate mysogonism. Unnecessary surgery is taking place with consequent damage e.g. **caesarians**, hysterectomies, ovaectomies. At a recent B.M.S. conference a gynaecologist, who lost civil cases involving the unlawful removal of healthy ovaries, openly advocated wholesale ovaectomies in all women over child-bearing age, on the grounds that a percentage of them may develop ovarian cancer. One wonders what the reaction would be if he had proposed wholesale castration of men over 45 on the grounds that 3% of them may develop testicular cancer! Some doctors obviously consider women’s bodies not as vessels to be repaired but as “gold-mines to be plundered”.

CHILDREN

Children are a vulnerable group, who often have little say in their medical treatment.

⌘ BIRTH - the most dangerous episode in anyone’s life

The use of birth inducing drugs in the interests of ward management, rather than the child, concerns us greatly.

- VACCINATIONS- important in eliminating childhood killer diseases - loss of public confidence due in part to the failure of the N.H.S. to take responsibility for past disasters, associated with contaminated vaccines, has unfortunately resulted in a drop off in vaccination rates.
- UNOFFICIAL CLINICAL TRIALS - medicines and equipment are rarely licensed for children, so that children e.g. in paediatric wards may be subjected to ‘unofficial poorly monitored clinical trials’ Recent cases include an anti-asthma drug and a new ventilator.
- DANGEROUS MEDICATION e.g. steroids for asthma or behaviour modifying drugs for ADHAS.
- ABORTION although some members are strongly pro life, we have, as yet no agreed position.
- We wholeheartedly endorse the appointment of an INDEPENDENT COMMISISONER FOR CHILDREN..

ELDERLY

In an ageing society where the percentage of people over 55 will dramatically increase in the future, **it is important** that we look at how we treat old people.

- ⌘ Treatment or intervention decisions based on the Q.A.R. Y. (Quality Age Related Years) discriminates against the elderly.
- ⌘ Rationing based on “value for money” can also affect the mobility and quality of life of our elderly.
- ⌘ Callous and uncaring treatment of terminally ill elderly. Thank heaven for hospices!
- ⌘ With relaxed attitudes to euthanasia ‘mercy killing’ is on the increase as is D.N.R. (DO NOT RESUCITATE) instructions.
- ⌘ Old Peoples’ Homes vary greatly in quality of care and the profit motive dominates. The closure of geriatric wards/units is a factor.

THE PRINCIPLE OF INFORMED CONSENT

The principle of informed consent, i.e., not only consent, but consent with full knowledge, must be clearly established. **The** recent Organ Retention Scandal has highlighted this issue. Old, arrogant, paternalistic attitudes must give way to a climate where patients are empowered, given autonomy and consulted.

- **KNOWLEDGE** - information about the procedure, treatment or surgery needs to be **HONEST**. Medical professionals tend to inflate success rates and minimise risks involved. It should also include **EVIDENCE** of the need for treatment e.g. tests, scans, x-rays etc., and also knowledge of alternative treatments available, including other **CONSERVATIVE** forms of treatment.
- **PERSONNEL** - who is performing the procedure? In many cases patients have an expectation that treatment/ procedure/ surgery/ will be performed by a senior professional e.g. consultant surgeon dealing with them. The cause of many mishaps is, for example, a junior surgeon performing complex surgery without even the supervision of a senior surgeon.
- **FRAMING of CONSENT FORMS** - most consent forms carry a clause, allowing medical professionals to carry out “any additional procedures, treatments or surgery, as deemed necessary”. This is often interpreted very liberally.
- ⌘ **CONSENT BY PROXY** - we need clear guidelines where consent is given by relatives and not the patient e.g. children, mental patients and unlit patients.
- ⌘ **WHEN SHOULD CONSENT BE SOUGHT?** Obviously seeking written consent for every procedure or minor treatment would hamper effective working and clog the system. However treatments which carry a **QUANTIFIABLE RISK** e.g. epidurals and ooscopies should require consent.
- ⌘ **SHOULD CONSENT ALWAYS BE IN WRITING?**
- ⌘ **EMERGENCY TREATMENT** requiring instant action, needs to be made an exceptional situation in consent terms.
- ⌘ **DISCIPLINARY / CRIMINAL JUSTICE MEASURES** - where consent was not sought or given or where consent specifically excluded further treatment e.g. removal of ovaries during gynaecological procedures The English Ovary and Hysterectomy Society funded a criminal case on behalf of a member who specifically excluded removal of her ovaries in her consent form. They lost the case!

HEALTH CARE AND HUMAN RIGHTS

In Human Rights terms access to appropriate and safe health care is of course not an absolute right, as it is always subject to the resources of the state and is in many states funded wholly or in part by private health insurance schemes, which somewhat reduce the responsibility of the state. However in the U. K. we have a publicly funded National Health Service based on need and not on the ability to pay.

N. H. S. PLAN. The recently published N. H. S. Plan for the next ten years, does in fact strengthen the rights of the patient, as it appears, incredibly to promise to provide what people “want” (“preferences”) as opposed to what they “need” or can be afforded. It also promises a “Comprehensive Service” and one that will be “designed around the patient” (what on earth was it designed ~~around~~ before!) In view of the increased expectations of what health care can provide and the huge expense of new techniques and medication we wonder if this is in fact achievable. The view of ~~most~~ experts is that given projected resources, facilities and **staffing** levels, it will be the devil’s own job to deliver.

In real terms the N. H. S. budget doubled in the decade 1990 - 2000, and there is no reason to believe that this trend will not continue. Does a “Comprehensive” Service mean that many health treatments, not currently fully funded, will now be funded? Examples include podiatric care, **sex-change** operations, infertility treatment, cosmetic surgery, optician care, prescriptions. **Does** it mean that M. S. sufferers will not now be denied Interferon? Will the N. H. S. provide **neuro - transmitters** which cost 520,000 each to the 2000 sufferers of Parkinson’s disease in N. Ireland, and **which** would dramatically improve their quality of life? We doubt if this will happen, and that “**prioritisation**” and “rationing” of services and use of “value for money” and Q. A. R. Y **criteria** will continue to be used.

In conclusion, we think it is obvious that rights to health care and treatment can only be framed in terms of access to **care**, which is freely available to any other member of society with a similar condition or in similar circumstances. Most National Health Services are based in fact on the premise of ‘the greater good of ~~the~~ greater number’ and many Third World Countries deliver a good basic **health** service on very meagre budgets.

However we would argue that **EXTRAORDINARY STEPS** need to be taken to address the needs of medical negligence victims, and **that** the N. H. S. should accept responsibility in these situations.

IMPLICATIONS OF THE 1998 HUMAN RIGHTS ACT

Of the 18 articles, the ones most likely to have an impact on patients and particularly medical negligence victims are:

ARTICLE 2 THE RIGHT TO LIFE

- ⌘ Particularly in connection with resourcing decisions which may lead to fatal outcomes or where the lawfulness of withdrawing treatments is challenged for example, objections to switching of life - support machines or “do not resuscitate” instructions.
- ⌘ Under this article, the failure to disclose a medical error or mishap, which may result in the death of the patient or seriously compromise their long - term health and future access to health care can be challenged.

ARTICLE 3: PROHIBITION OF TORTURE, INHUMAN AND/OR DEGRADING TREATMENT / PUNISHMENT.

- ⌘ Under this article mental health patients could oppose treatment e.g. E.C.T. (about which we have concerns) Relatives could oppose the use of ‘soft **cosh**’ drugs for a range of patients including the **infirm**, mentally ill, and elderly confused.
- ⌘ Victims of medical negligence could challenge many aspects of the ONGOING ABUSE which follows a medical disaster e.g. Denial of treatment, unnecessary further investigations and surgery including the removal of healthy organs, aborted appointments and labelling as “psychologically dysfunctional”.
- ⌘ Relatives of deceased victims could challenge a system, which prevents them from putting their grief behind them.
- ⌘⌘ Respect for HUMAN REMAINS may also be enforced under this article

ARTICLE 5: THE RIGHT TO LIBERTY AND SECURITY

- ⌘ This article could be invoked by mental health patients (and also communities who seek protection from them).
- ⌘ Poorly controlled / monitored CLINICAL TRIALS involving children, paid volunteers, or unpaid patient volunteers, where the principle of **informed** consent is often ignored and where we need clearer guidelines, is an ISSUE under this article.
- ⌘ The general principle of INFORMED CONSENT is strengthened by this article.

ARTICLE 6:- THE RIGHT TO A FAIR TRIAL

- ⌘ We feel that doctors / other medical professionals stand to benefit, as the article may strengthen their safeguards.
- ⌘ Under this article, we intend challenging the entire N.H.S. Complaints Procedures including Watchdog Councils, the Health Ombudsman and the G.M.C. as a fair and impartial system.
- ⌘ Specifically, we intend to challenge the stance of the G.M.C. and other professional councils to describe their ‘courts’ as impartial and independent tribunals.

ARTICLE 8: THE RIGHT TO RESPECT FOR PRIVATE AND FAMILY LIFE.

- ⌘ This article has implications in upholding parents' rights, as in the recent case of the co-joined twins, or refusing treatment on religious grounds e.g. Jehovahs' Witnesses and blood transfusions
- ⌘ There may also be implications to this article bearing upon access to medical records and the alteration or destruction of such records.
- ⌘ It can also be used to contest the HARRASSMENT to which medical negligence victims are subjected and which are a clear invasion of their privacy. E.g. surveillance, phone calls, or entering property.
- ⌘ We may also use this article to challenge lack of response by our police and criminal justice system to clearly identified criminal activities linked to health care and medical negligence.

ARTICLE 12: - THE RIGHT TO MARRY AND FOUND A FAMILY

- ⌘ This article could be used by an infertile couple to challenge denial of treatment.
- ⌘ It could also be used by women who have had unnecessary sterilisation e.g. removal of healthy ovaries or unnecessary hysterectomies.

ARTICLE 14 PROHIBITION AGAINST DISCRIMINATION

- The 'lottery of **postcode** rationing' could be in direct conflict with this provision.
- Within N. Ireland, the standard of hospital care one can expect to receive varies geographically and a disproportionate number of mishaps occur in our understaffed, under-funded local or 'rural' hospitals. In future arrangements, patients may have to make a choice between good **safe** care and convenience.
- Variations in **WAITING LISTS** between boards e.g. The Western versus the Northern Boards is clearly discriminatory.
- **G.P. FUNDHOLDING** is contrary to the spirit of this article.
- Women and the elderly face discrimination
- Many **groups e.g.** haemophiliacs could challenge denial of medication or treatment e.g. a safe, but more expensive, synthetic factor 8 serum.
- Of course medical negligence victims face discrimination and under this article, we intend challenging many aspects of their ongoing abuse and ill-treatment.

HOPE FOR THE FUTURE

We are enormously encouraged by some recent developments

. A NATIONAL EARLY WARNING SYSTEM FOR THE N.H.S

The Health Secretary has promised to set up a new system to help prevent medical accidents. It will **include:-**

1. a National Mandatory Reporting System to log all failures, mistakes, errors and 'near misses'
2. a single National Database to analyse and share lessons learned from accidents and near misses
3. Replacing the Climate of Blame with a reporting and questioning culture.
4. Improving **N.H.S.** Investigations and Enquiries to ensure results are fed into the national database.
{we hope that N. Ireland will participate fully in all aspects of this proposed system)

⌘ A PERCEPTIVE CHANGE IN ATTITUDES **among** some, (particularly young) medical professionals.

- NEW EDUCATIONAL GUIDELINES for training of medical professionals e.g. MORAL ETHICAL MODULE
TRAINING IN HUMAN COMMUNICATION
A TEAMWORK APPROACH

⌘ NEW APPROACHES ▪ some hospitals have pioneered new approaches to handling clinical accidents

(a). CHESTERFIELD and NORTH DERBYSHIRE ROYAL HOSPITALS

Since 1996 this trust has introduced a mandatory system to report all clinical incidents and fostered a no ▪ blame culture, where incidents are investigated and lessons learnt..

(b) KIDNEY UNIT, QUEEN ELIZABEH MEDICAL CENTRE BIRMINGHAM

Doctors in the renal department have set up a computerised prescribing system containing patient details and comprehensive drug details. The computers issue warnings of errors and, in just 10 months, 60 potentially fatal deliveries of medication were avoided.

[We would like hospitals in N. Ireland to adopt similar approaches.]

HEALTH INSPECTORATE

Some changes are taking place but progress is patchy and uncoordinated. There is still an absence of effective administrative, enforcement, regulatory and disciplinary procedures. Government reaction to recent medical scandals is to set up another bureaucratic body to deal with the issue, often overlapping or running parallel to existing bodies e.g. C. O. M. A., N. I. C. E., or more recently N. C. A. A. They have set up no less than nine such bodies in the last two years and must, by now, be running out of acronyms! In addition we have a multitude of professional bodies dealing with specific narrow issues.

We would like the Secretary of State for Health to **'grasp the nettle'** and establish an INDEPENDENT CENTRAL BODY **with** real powers e.g. a Health Inspectorate or 'OFDOC' to drive and monitor change. The lessons of the Railways Fiasco should teach us that a plethora of regulatory agencies just does NOT WORK.

In other areas of life e.g. education or policing, we do not accept that bodies of workers or service providers can safely be **left** to regulate themselves. Why not in Health Care? However we would expect strong opposition from medical professional bodies to the formation of that independent regulatory authority. They must accept, however that the professional regulatory councils e.g. The General Medical Council, have shown themselves totally incapable of acting in the interests of the public rather than their members. The performance of the G. M. C. in recent high profile scandals has completely undermined its position. In the most recent Organ Retention Scandal, they initially washed their hands of it, saying it was a "matter for doctors and managers in individual hospitals". Then, under pressure they tossed a sacrificial lamb to an outraged public!. In public perception, in the opinion of the 10,000 to 15,000 who annually make largely fruitless complaints, and even in the view of several of the lay assessors, they brought in to lend them an air of independence, THE G M.C. IS A FAILED BODY.

The general public have wholeheartedly welcomed the work of the Financial Services Agency which is forcing reforms and changes in the area of banking and **insurance**, pensions and investment - and it is of course long overdue. They would also welcome A HEALTH SERVICES AGENCY doing the same for the delivery of health care. How many more scandals can we endure before someone in authority realises this?

In conclusion, SET UP A HELTH INSPECTORATE / OFDOC/ HEALTH SERVICES AGENCY, AND DO IT NOW!

ARBITRATION TO SETTLE MEDICAL NEGLIGENCE CLAIMS

Some Health Boards in England have set up ARBITRATION TRIBUNALS to deal with medical negligence cases, following recommendations in the WOOLF REPORT. We are following their work with some interest.

Many medical negligence victims who have had their cases settled in this way, have positive things to say about it.

It avoided the need for a protracted, acrimonious and confrontational legal case”

“It ‘cleared the air’ and I was then able to get honest and fairly helpful remedial health care”

“The compensation was not generous, but the process was quick and was not stressful”.

“Since I had neither the money nor the stamina to run a legal case, I would have got nothing. This way I got an apology, an explanation and some compensation.“.

Perhaps this is the way to go. The only reservation of course is the level of compensation which, in cases involving 24 hour care for the remainder of their lives or where the victim was the sole breadwinner would not be adequate. However in very many cases, victims or relatives are not looking for compensation. There is some evidence, particularly from the United States, that an open accountable system throughout the N.H.S. would ACTUALLY COST LESS. (We have asked our Health Minister for costings of medical negligence, including legal and complaints departments in Boards and Trusts, legal costs in cases, insurance costs for hospitals and health professionals, together with the cost to society in terms of health and social care, incapacity and disability allowances, and the loss to society of economically active people. We are still waiting for a reply! }

SUMMARY OF OBJECTIVES

1. FULL AND IMMEDIATE DISCLOSURE OF MEDICAL MISHAPS.
Coupled with an open and accountable system.
2. A HEALTH INSPECTORATE / 'OFDOC' / HEALTH SERVICES AGENCY.
3. PATIENT SAFETY made a priority.
4. INFORMED CONSENT principle properly fastened.
5. CLINICAL TRIALS ▪ guidelines and safeguards
6. DISCRIMINATION ▪ against women, children, elderly, AND medical negligence victims outlawed
7. MEDICAL RECORDS ▪ safekeeping and property/ access strengthened.
8. COMPENSATION ▪ a fast, stress-free system via complaints/ legal / arbitration procedures.
9. DEATHS - an improved process e.g. inadequate Inquest System replaced by **something** akin to the Scottish Fatal Accident Enquiry.
10. CRIMINAL JUSTICE SYSTEM ▪ an end to the privileged, protected position of medical professionals (and administrators).
11. SPECIAL, **EXTRAORDINARY** MEASURES to help medical negligence victims e.g. payment for referral / treatment to specialist units within or outside the U.K.