

Stephen McMahon Stephen, is co-founder and Director of the Irish Patients Association. (IPA). He worked for a multi-national Oil company for 30 years. The driving force behind its establishment were personal family events, and the realisation that there was no one advocating for Patients needs and importantly their rights to be protected as a cross disease advocacy. He deals with approx. 500 patient cases per annum, many are experiencing difficulty in having their voices heard, this insight is a valuable contribution he brings to many levels within the social and policy levels both nationally and internationally some of which effect change within the system. His maxim is “Change and reform in our health service should not be preceded by preventable funerals and injuries to patients” and that all decisions must keep the patient at the center of the healthcare system.

8th Dec 2016

Opening Statement to the Oireachtas Committee for Health & Children

by

Stephen MCMAHON

Governance

Good Morning: Thank you for your invitation to talk to you today. I would like, to introduce you to my fellow patient advocates who are very experienced and respected.

While we respect that this committee is hearing from a whole range of stakeholders; as patient advocates, we are calling for a statutory requirement on health care professionals to disclose to patients when an adverse event has occurred.

My Older brother Raymond has cerebral palsy and is paraplegic, the result from an injury at his birth. My wife Fiona suffered severe post-natal depression following the births of our children, these and other experience led us to found the Irish Patients Association.

Almost to the minute, 21 years ago, the Irish Patients Association was launched on the RTE Program To-Day with Pat Kenny. At that time patients were disempowered, they had no voice, they were talked down to by the system, many were kept in the dark, the patients charter was nothing more than a piece of paper with no real commitment to deliver its aspirations, even the word patient advocacy was new, and yes if you were on a waiting list the advocate you would go to was your TD.

We have been involved in many areas of the health care system over the years, always faithful as best we can to our patients and their families. By keeping them at the centre of all decision making

Reform has been glacial, however much has been done to improve quality and safety and we welcome and support this, but this is a matter of Trust , Trust in the system for patients and wider society, and it is also a matter of rights,

We can't remember all we can remember a few –

Mrs Rebecca O Malley Cancer Misdiagnosis

Mr Kevin Murphy RIP whose Mum Margaret is with us this morning

Mrs Savita Halappanavar RIP Delayed treatment

Ms Bimbo Onanuga RIP Medical Misadventure

Ms Dhara Kivlehan RIP delayed treatment

Mr Colin Evans RIP Medication error

Baby Mark Molloy RIP whose Dad Mark senior is with us this morning.

Mr Gerry Feeney RIP Aspects of hospital care ‘completely unacceptable’

Do we have a problem?

Yes, we do I refer you to a recent study published in the British Medical Journal Feb 10th 2016. Titled "The Irish National Adverse Events Study (INAES): the frequency and nature of adverse events in Irish hospitals" a retrospective record review of 2009 data by INAES NATASHA RAFTER ET-AL

one in eight patients admitted to hospital during 2009 experienced adverse events of those 20.8% moderate recovery within a month, 8.60% permanent disability <50% and in 6.7% contributed to death of the patient's How many of these patients were told of that the mistake was avoidable?

I believe this is just the tip of the iceberg, as no adverse events were studied in community, family doctors, nursing homes, or the impact of our unequal access to healthcare for those waiting too long to be seen or get their surgery

Look at how the issue of consent has changes the doctor patient relationship over the past 20 years, in the HSEs own policy document it states:

"It is a basic rule of common law that consent must be obtained for clinical examination, treatment or investigation. The Irish Constitution reaffirms this rule, as does international law. Therefore, any exceptions to the rule would be subjected to intense judicial scrutiny since the purpose of the rule is to uphold one of the most basic of all rights i.e. the right to bodily integrity. - .. The argument for consent as an indispensable precursor to treatment is born out of the concept of Patient autonomy, which in tum is based upon the rights of individual self-determination and of bodily integrity under Article 40.3 of the Constitution."

Simply put, a Patient does not consent to an adverse event, as stated above it is not lawful to do an examination treatment of investigation without such consent surely the patient has a statutory right to be told when such a violation of consent occurs or that the management of the "services advise the patient if their role has caused the event?

Who is best served by the establishment's current position, that there should not be a statutory obligation for the patient to be told?

Management. Policy Makers and other agencies have an obligation to disclose adverse events for example. The Medical Council of Ireland is not an Inquiry as it certainly does not use information it has and knows the consequences - of issuing it or not.

In addition, supporting the law , Patient Safety / Advocacy Agency must be independent of Department of Health and the HSE similar to HIQA which In my view is a jewel in the regulatory crown, the language of advocacy is moving from the passive participation to the language of rights and active involvement in many ways.

"Change and reform in our health care system must not be preceded by preventable funerals and injury to patients"

Make open disclosure the law because its needed and you can do it

I would like to address the issue of accountability by management and public servants who govern the day to day system during your questions

Thank You

Margaret MURPHY Following the death of her son as a result of medical error, Margaret Murphy, External Lead Advisor of the World Health Organisation's (WHO) Patients for Patient Safety Programme, has been actively involved as a patient safety advocate. The focus of her work relates to seeing adverse events as having the potential to be catalysts for change as well as being opportunities for learning, identifying areas for improvement and preventing recurrence. She promotes this viewpoint at local, national and international levels. Her area of particular interest is education as a vehicle to achieve sustainable culture change. Margaret partners and collaborates in the areas of Policy making, Standard Setting, Professional Regulation, Education and Research.

It is important to understand that disclosure is not about blame neither accepting blame nor apportioning blame. It is about demonstrating integrity and true professionalism, it is about preserving the relationship of trust between doctor and patient, it is about learning and improvement.



Exhortations, training, resolve alone will not work or will take too long to work. The absolute need for mandatory open disclosure underpinned by legislation is evidenced by:

1. An inalienable right of any patient entrusting their own care and that of loved ones to our healthcare system to have the assurance that in the event of error, open disclosure will be practiced, that learning will occur and that improvements to prevent recurrence will be put in place. The continuing mantra from those exiting our courts is: 'We just do not want it to happen to anybody else'.
2. The need to break the cycle of deny and defend which catapults patients and families into a litigation process to gain access to truth and acceptance of responsibility. I will illustrate with an example from our interactions following Kevin's death.
3. The entitlement of families to the Respectful Management of Serious Clinical Events in accordance with the process outlined by the IHI White Paper. Closing ranks, lame excuses, collegiality and inappropriate responses undermine the system we are trying to bring to a state of excellence.
4. It will support staffs, especially front-line staffs in 'doing the right thing' because with legislation they **must do so** in contrast to putting their heads above the parapet. It will address the shared abandonment which staffs and families often experience in the aftermath of events - I will give an example of the Registrar
5. The need to move away from the language of 'encouraging', 'promoting' open disclosure to saying 'disclosure is what we have to do, **because it is the law**'.
6. The need to dispel the myths. It will not result in an escalation of litigation - The Michigan Experience. The experience of Dr Rick Van Pelt and his patient Linda Kenny. Neither will it result in avoidance of reporting - it is the law. 90% of the respondents to the Irish Medical Council Survey said they trust doctors to tell the truth. Legislation will help doctors to not betray that high level of trust placed in them by vulnerable patients and concerned carers.
7. Strengthening the effectiveness of the HSE training initiative in relation to disclosure - ensuring that disclosure is everyone's business.
8. For me as an individual it is important because I was present at Kevin's birth - I know every detail of that birth. I was also present when he died and as his mother I needed and deserved to know everything about the circumstances which brought that about. But over and above that I needed to be assured that lessons would be learned, that those lessons would be disseminated all in the hope of preventing recurrence. To err is human to cover up is unforgivable but to refuse to learn is inexcusable

Mark Molloy Mark is married to Roisin and they have 5 sons, Gavin 14, Adam 12, Luke 9, Jeff 7 and Mark Jnr who passed away moments after delivery in January 2012.

Since the death of their son, Mark and Roisin have been active in striving to improve health services nationally and have been instrumental in effecting change across a number of historically challenging areas for service user across the entire health spectrum.

They are currently campaigning for the introduction of a legislative based Accountability Framework supported by further Open Disclosure legislation for all health care practitioners in Ireland, arguing that, from their experiences since Mark Jnr's death, this represents the biggest single obstacle to health care reform facing the state.

Mark qualified with a BSurv in Quantity Surveying and is currently employed with the construction firm Severfield (NI) Ltd where he manages a team of project surveyors

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Mark Molloy

Since the death of our baby son, Mark, in 2012, my wife Roisin and I have been active in seeking reform to our health service in order to attempt to implement changes to the many serious patient safety issues and obstacles that we have encountered during this time. We would like to take this opportunity to welcome the many improvements and patient safety supports and initiatives that have been introduced over the past 3 years.

Our experience is of a system where great lengths will be pursued to contain adverse events by people at all levels and in various roles who appear to have a fall-back position of complete impunity and in the knowledge that, while their actions may have catastrophic consequences for patients and a significant affect of front line staff, there are no effective mechanisms in place to make them accountable for poor performance, while the state will continue to pick up the tab for the financial consequences of their actions. It is this lack of a Statutory Accountability Framework that we feel is the single biggest impediment to healthcare reform in Ireland.

In the immediate aftermath of Mark's death, we asked the management of the maternity unit why our son had died. We essentially looked for Open Disclosure, but were mislead. Before Roisin left hospital 7 days later we asked the same question and were mislead again. We know now that they had the answers at that time. We met the management of the hospital 5 weeks later and were once again not given the answers that they had. As each tier of HSE management did not give us the answers that were known to them about Mark's death, we moved to a higher tier all the way to national Director Level, and were, as Minister Varadkar said last year, lied to, many times. Of course, as we now know, that our experience was much the same as many other people nationally.

I have read through the transcript of the Committee's sitting with the Chief Medical Office, Dr. Tony Holohan and Dr. Kathleen MacLellan of the DoH and agree with the vast majority of their submissions, particularly in relation to making Open Disclosure mandatory within the HSE for a certain level of Adverse Event and above. What we disagree on is whether Open Disclosure should be voluntary or statutory.

As I speak to you today, the management investigation that resulted from Roisin and my last appearance before this committee in May 2015 is now over 1 year overdue for completion and estimates suggest it will be at least March 2017 before it is complete. This investigation is about non disclosure by senior HSE management and this is particularly where we feel voluntary Open Disclosure within our health service collapses.

It is no secret that there is an apparent significant disconnect between HSE front line staff and management and yet, the enormity of the cultural shift that this voluntary initiative would require would demand full top-down buy in and support if it were to be effective. How can we expect front line staff to voluntary Open Disclose when they witness management going to such lengths to contain incidents? Unfortunately, it simply will not happen.

While, to err is human, self preservation is one of our most basic instincts.

We submit to the house that the battle to encourage an Open Disclosure culture within our health service is long since lost and only through the introduction of statutory based Open Disclosure, most importantly overseen by a broader Legal Accountability Framework for all healthcare professionals in Ireland, can we have confidence that patients will be appropriately informed when things go wrong.