The patient experience story as a catalyst for change
Patients for Patient Safety

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External Lead Advisor
Patients for Patient Safety
WHO Patient Safety

In honour of
those who have died,
those who have been left disabled,
our loved ones today,
we will strive for excellence,
so that all people receiving healthcare
are as safe as possible,
as soon as possible.

This is our pledge of partnership

The National Patient Safety Collaborative Learning Event
23rd May, 2017

- The Patient Experience as a Catalyst for Change -
INTRODUCTION

- Addressing the heart of the matter – the patient and family experience of care

- Recognising the potential of patient experience to drive improvement in all aspects of care
A Personal Experience

- MOTIVATION TO ENGAGE IN ADVOCACY
- The preventable nature of adverse events
- Damage limitation and its effect on learning and improvement
- The potential of adverse events to be catalysts for change
The Effectiveness of the Story to stimulate insight and reflective learning

Indian Saying:
Tell me a fact ...and I’ll learn
Tell me a truth ...and I’ll believe
Tell me a story ...and it will live in my heart forever

“Facts do not change feelings and feelings are what influence behaviours. The accuracy, the clarity with which we absorb information has little effect on us; it is how we feel about the information that determines whether we will use it or not”.
- Vera Keane, 1967
SIMPLE MEASURES SAVE LIVES
Official Data : An Example

Deimhniú bás ar na h-éisiúint de bhun na hAchta um Chláirí Breitheanna agus Básanna 1863 go 1972.

DEATH CERTIFICATE issued in pursuance of Births and Deaths Registration Acts 1863 to 1972.

<table>
<thead>
<tr>
<th>Básanna a Chíraítheach</th>
<th>i gCéantar an Chláiríthea</th>
<th>i gContúr an Chláiríthea</th>
<th>i gCéantar an Chláiríthea Maíoirseachta do</th>
<th>i gCéantar an Chláiríthea</th>
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<td>Umh. No.</td>
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<table>
<thead>
<tr>
<th>Cúige</th>
<th>Date and Place of Death</th>
<th>Name and Surname</th>
<th>Sex</th>
<th>Staid</th>
<th>Age last Birthday</th>
<th>Cúise Bás Dheimhnithe</th>
<th>Certified Cause of Death and Duration of Illness</th>
<th>Signature, Qualification and Residence of Informant</th>
<th>An data a Chíraítheach</th>
<th>Síniú an Cláirítheach</th>
<th>Signature of Registrar</th>
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<tbody>
<tr>
<td>1</td>
<td>1933</td>
<td>Hughan</td>
<td>Male</td>
<td>Single</td>
<td>21 yrs.</td>
<td>Multi-Organ Failure</td>
<td>Parathyroid tumour</td>
<td>Daniel F. McEvilly, M.D. 1939</td>
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Déimhmise leis seo go bhfuil se le Tháifleadh Uimh.
I hereby certify that the foregoing is a true Copy of the Entry No. 174 in a Register Book of Deaths in my custody.

Cláirítheoir * (Maíoirseachta) na Breitheanna agus na Básanna
(Superintendent) Registrar of Births and Deaths

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<thead>
<tr>
<th>Mile</th>
<th>One Thousand</th>
<th>Hundred</th>
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<td>170</td>
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*PRIOR TO ALTER THIS DOCUMENT OR TO UTTER IT SO ALTERED IS A SERIOUS OFFENCE

World Health Organization

Patient Safety
A Worldwide Asset for Safer Health Care
Kevin The Person
8 Days before admission to hospital
The Questions

Simple questions.....

Why did Kevin die?

What went wrong?

We need to know and we need to understand
Every Point of Contact Failed Him...
The Unfolding Story 1997-1999

Persistent back pain – GP Visits, X-Rays

Orthopaedic Surgeon – Bone Scan, Blood Tests

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<tr>
<td>Calcium</td>
<td>3.51 m/mol</td>
<td>(2.05-2.75)</td>
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<td>Described as ‘inconsistent with life’.</td>
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<td>Creatinine</td>
<td>141</td>
<td>(60-120)</td>
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<tr>
<td>Urate</td>
<td>551</td>
<td>(120-480)</td>
</tr>
<tr>
<td>Bilirubin Direct</td>
<td>9.9</td>
<td>(0-6)</td>
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<tr>
<td>Alk Phosphate</td>
<td>489</td>
<td>(90-300)</td>
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YOU IGNORE AT YOUR PERIL
THE CONCERNS OF A MOTHER
Peer Review

“The combination of bone pain, renal failure and hypercalcaemia in a young patient points either to a diagnosis of primary hyperparathyroidism or metastatic malignancy and these ominous results should have been investigated as a matter of urgency”.

“Kevin would have had surgery to remove the over-active parathyroid gland. He would have been cured and would still have been alive today.”

“All the evidence indicates that the patient was suffering from a solitary parathyroid adenoma at the time, removal would have been curative with a normal life expectancy”

Research 96% Success; 1% Complication Rate
The Post-It
Every Point of Contact Failed Him…
The Shortcomings
Primary Care

- Inability to recognise seriousness of Kevin’s condition
- Appropriate interventions not taken
- Selective and incomplete transmission of information.
- Non receipting of vital information
- Absence of integrated pathways
- Link between behaviour and test results not made
- Developing neurological problems ignored
- No evidence of tracking of his deteriorating condition

ABSENCE OF DIRECT COMMUNICATION
WITH THE PATIENT
The Shortcomings
Secondary Care

- Treatment at Registrar level
- The team dynamic
- The impact of a weekend admission
- Patient asked to accommodate system
- Expectations of a Tertiary Training Hospital
The Response

- Initial humane reaction from individuals
- Damage limitation
- Absence of transparency, disclosure, honest dialogue
An Adverse Event – The Aftermath

Reluctance to be open and transparent

Confidence in ascertaining the truth shattered

Closing ranks
Lame excuses
Muddying waters

Forced to reluctantly pursue the litigation route
Legal Route to Finding Answers

- System favours defendants
- Disempowerment of plaintiff
- Plaintiff takes huge personal risks
- “David and Goliath” experience
- Wearing-down process
- Lack of compassion
- Focus needs to be on learning rather than on blame
“It is very clear to me that Kevin Murphy should not have died.”

Judge Roderick Murphy at High Court Ruling
May 2004
ADVERSE EVENTS AND HEALTHCARE STAFF??
A Wish List : Do it Right!

- Observe existing guidelines, best practice and SOP’s. Be prepared to challenge each other in that regard.

- Following adverse outcomes undertake “root cause analysis” "system failure analysis"/"critical incident investigation”.

- Communicate effectively within the medical community and with patients.

- Keep impeccable records and refer constantly to those records.

- Listen to and respect patients and families.

- Know your personal limitations.

- Replicate what is good and be always vigilant for opportunities to improve.

ACKNOWLEDGE ERROR AND ALLOW LEARNING TO OCCUR.
A Wish List Contd

- Learn and disseminate that learning
- Practice dialogue and collaboration – meaningful engagement with patients and families
- Create a coalition of healthcare professionals and patients
- Be honest and open and seize the opportunity to give some meaning to tragedy
- It could not happen here – 5 most dangerous words

ACKNOWLEDGE ERROR
AND ALLOW LEARNING TO OCCUR
A Resolution going Forward
- RESCUE and CO-PRODUCTION -

More than anything, what distinguishes the great from the mediocre, is not that they fail less, it is that they rescue more.
- Atul Gawande

In honour of those who have died, those who have been left disabled, our loved ones today, we will strive for excellence, so that all people receiving healthcare are as safe as possible, as soon as possible.

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My Call for……

- Care delivered with Head, with Heart, with Hand - *BMA*
- Reporting and Learning
- Transparency, Accountability, Open Disclosure
- Patient engagement/involvement as a ‘right’

“To err is human, to cover up is unforgivable but to fail to learn is inexcusable.”

-Sir Liam Donaldson, Chair, WHO Patient Safety