AN BORD ALTRANAI\S

- Placing the Patient First -

Dublin June, 2008

Margaret Murphy, Patient Advocate
Member, Patients for Patient Safety Steering Group
WHO World Alliance for Patient Safety
INTRODUCTION (1)

• The patient journey
• The family journey following the adverse event.
• Exploring the possibilities of a better way forward.
• Opportunities offered by the Patients for Patient Safety strand of the WAPS
• Partnership, collaboration, meaningful patient and family engagement = healing for patients, families, clinicians = healthcare improvement.
INTRODUCTION (2)

• Personal Background & Motivation
• Relevance and impact of patient experience
• Patient experience as a catalyst for change
• The challenge of learning from the patient experience – acknowledging non-compliance and the mismatch between the actual and the ideal in relation to patient safety
Official Data : An Example

<table>
<thead>
<tr>
<th>Uimh.</th>
<th>Data agus Iomáin Básaí</th>
<th>Aonam agus Saine</th>
<th>Gnéas</th>
<th>Staid</th>
<th>Anois an Lá Bheithre</th>
<th>Cúim, Cairm nó Sli Bheithre</th>
<th>Cais Bás Dheireadh agus Fad an Turas</th>
<th>Sinse, Cáilteacht agus Iomáin Conaithe</th>
<th>An Dáta a Chaithd</th>
<th>Sinse an Chláraitheora</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1999</td>
<td>Kavan Hughes</td>
<td>Male</td>
<td>Bride</td>
<td>31</td>
<td>Multi-agus Fadura</td>
<td>Hypertension</td>
<td>certified</td>
<td>October 1999</td>
<td>S. O'Canaigh</td>
</tr>
<tr>
<td>2</td>
<td>33 Tracton Place</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Deimhinse leis go bhfuil a chuid an Bháis a gholstone thuas nó. I hereby certify that the foregoing is a true Copy of the Entry No. 170 in a Register Book of Deaths in my custody.

Mile
One Thousand

<table>
<thead>
<tr>
<th>Síle</th>
<th>gCéad</th>
<th>maet'ine</th>
</tr>
</thead>
</table>

TO ALTER THIS DOCUMENT OR TO UTTER IT SO ALTERED IS A SERIOUS OFFENCE
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

<table>
<thead>
<tr>
<th>Test</th>
<th>1997</th>
<th>1999</th>
</tr>
</thead>
<tbody>
<tr>
<td>Calcium</td>
<td>3.51</td>
<td>(2.05-2.75)</td>
</tr>
<tr>
<td>Described as ‘inconsistent with life’.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Creatinine</td>
<td>141</td>
<td>(60-120)</td>
</tr>
<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>
</tr>
<tr>
<td>Alk Phosphate</td>
<td>489</td>
<td>(90-300)</td>
</tr>
</tbody>
</table>
YOU IGNORE AT YOUR PERIL
THE CONCERNS OF A MOTHER
“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”
Every Point of Contact Failed Him...
<table>
<thead>
<tr>
<th>Test</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pot</td>
<td>3.6</td>
</tr>
<tr>
<td>Urea</td>
<td>9.9</td>
</tr>
<tr>
<td>Creat</td>
<td>21.4</td>
</tr>
<tr>
<td>Gluc</td>
<td>5.6</td>
</tr>
<tr>
<td>Alb.</td>
<td>4.9</td>
</tr>
<tr>
<td>BC1</td>
<td>1.24</td>
</tr>
<tr>
<td>ALC. Pre</td>
<td>8-5</td>
</tr>
<tr>
<td>AST</td>
<td>0.4</td>
</tr>
<tr>
<td>LDH</td>
<td>6.2</td>
</tr>
</tbody>
</table>
Every Point of Contact Failed Him...
The Shortcomings

- 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
Shortcomings *Contd*…

• 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

- Defensive
- ‘Loyalty to colleagues’
- Muddying the waters – dissembling
  - e.g. Claims of inability to understand ‘layspeak’
- Attempts to shift responsibility
- Confidence in any hope of ascertaining truth shattered
- Excuses offered were unsustainable
- Expectation of professional and honourable conduct betrayed
The Post-It
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
“It is very clear to me that Kevin Murphy should not have died.”

Judge Roderick Murphy at High Court Ruling
May 2004
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
The Way Forward
- Barriers to Progress -

- Inappropriate responses and their role in relation to fuelling confrontation?
- Inaccessibility of partnership and collaborative opportunities to ordinary patients and families
- The culture of medical practice - a perception of infallibility and faultless performance
- Fears relating to litigation and loss of reputation.
- Excluding the patient and family from the change process.
- Neglecting to learn from industry
A Better Way

Sir Liam Donaldson

Chair, World Alliance for Patient Safety
Patients & Families – the Untapped Resource - World Alliance for Patient Safety

The perspective and partnership of patients, their families and health consumers all over the world...

- Central to the patient safety work of WHO
- Crucial to articulating the reality and identifying gaps in service
- Necessary to ensure services are driven by patient need and are authentically patient-centred
- Validates implementation of guidelines, processes and protocols.
- Ensures the patient voice in the global arena of healthcare
Formational Workshops
Champion Activities

- Patient safety commissions, task forces, committees, speaking engagements at conferences, etc
- Connecting with our country offices of WHO
- Establishing our own patient safety organizations.
- Writing in local or national publications and journals
- Networking.
- Fundraising
- Dedicated projects
  (i) advancing patient involvement/engagement
  (ii) understanding what patients and families want in relation to disclosure and learning from adverse events
Impact on and by Champions

“The Workshop united all efforts of patients from different regions of Ukraine. Now I can see that I am not alone in my desire to change the system. I am not alone in my grief also. There are some people that have passion to do something good in this domain. That Kiev workshop gave me more strength and more belief that we can do something.”

- F. Petkanych

Ukrainian Champions
Barbara Farlow
Ed Mendoza

Canadian Champions
A Better Way (2)
Disclosure, Openness, Transparency

• Dr Rick Van Pelt & Linda Kenney
• AMA Code of Ethics
• The Sorry Works Coalition
• US Mass hospital experience
• Canada, Australia and Denmark
RAPS Code of Ethics

- Conducting actions in compliance with the existing laws and regulations
- Being competent
- Being committed to continual learning while being able to acknowledge areas that are outside of your expertise.
- Not being unduly influenced by competing or conflicting interests.
- Being principled, consistent and possessing integrity
- Ensuring that information and communications, whether oral or written, are accurate and complete.
- Being able to withstand challenges to our views, while at the same time being accountable for mistakes.
- Being just in considering the interests of all parties.
- Being respectful of others – treating all individuals with dignity and courtesy.
W.H.O. / H.I.Q.A. Project

Driving Learning
while supporting patients, families
and clinicians when things go wrong

- Framework for Reporting and Learning
- Preserving the relationship of trust
- Giving meaning to tragedy
- Acknowledging error and allowing learning to occur
- Feedback to patients and families
PARTNERSHIP AND COLLABORATION

DIALOGUE

= POWERFUL CONVERSATION
Review communications processes, policies and procedures that hospitals use to respond to patients where there is a serious incident.

Senior management, together with clinicians, should introduce new arrangements for the effective delivery of patient-centred services that should be measured, monitored and published in an annual report.

A robust clinical governance framework should be adopted at local, regional and national levels.

Establish an effective, patient-focused communications strategy.

Administration arrangements to be strengthened to ensure clarity of designated levels of authority, reporting relationships and accountability; a transparent business planning and decision making process and the engagement and involvement of clinicians in the executive management process.
“To err is human, to cover up is unforgivable but to fail to learn is inexcusable.”

- Sir Liam Donaldson, Chair, World Alliance for Patient Safety

Thank You

June 2008

margaretmurphyireland@gmail.com