The Patient Experience as a Catalyst for Change
Margaret Murphy, WHO Patient Safety
A Webber Training Teleclass

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A World Alliance for Safer Health Care

Patients for Patient Safety

THE PATIENT EXPERIENCE AS A CATALYST FOR CHANGE

Margaret Murphy
Patient Advocate & External Lead
Patients for Patient Safety Programme
WHO Patient Safety

Hosted by Julie Storr
WHO Patient Safety

www.webbertraining.com January 24, 2013

INTRODUCTION

- The patient and family perspectives
- Management and Leadership styles
- Presentation Focus:
  - Learning from the patient experience
  - Patient Safety and the value of patient engagement
  - Management of adverse events
- Patient expectations - safe care, trusted relationships
- The patient as the constant in the continuum of care – and having greatest vested interest in the outcome.
- Demonstrating adherence to guidelines
- Applying improvement in the 'here-and-now'

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Working in Partnership with Patients, Families & Communities

- PFPS – collaborative partners and co-producers of safe care -
- Partnership as a key theme – patients, healthcare professionals, policy makers
- The shared goal of safe healthcare

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Patients for Patient Safety Workshops
214 Champions in 51 Countries – 13 Collaborating organisations

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The Untapped Resource
The Global Solution

Taking account of the perspective of patients, their families and carers in planning and delivering care is…

- 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
- A validation tool in relation to the implementation of guidelines, processes and protocols.
- Necessary to ensure the patient voice is heard

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- Core Values -

COLLECTIVE

OPENNESS

HONESTY

COLLABORATIVE PARTNERSHIP

MEANINGFUL ENGAGEMENT AND EMPOWERMENT

REDUCTION IN HARM DUE TO MEDICAL ERROR i.e. SAFER OUTCOMES

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Champion Activities

- Serve on patient safety commissions, task forces, committees
- Accept speaking engagements
- Act as advisers to various dedicated safety projects and research initiatives
- Engage with medical students and educators
- Partner with health providers at all levels
- Connect with our country offices of WHO
- Establish our own patient safety organizations.
- Write in local or national publications and journals on the topic of PS and PFPS

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Motivation

- The negative experience as a catalyst for change
- Raising awareness
- Identifying shortcomings to highlight improvement areas
- Promoting open disclosure – not about blame – relates to integrity and true professionalism

Making the Status Quo Uncomfortable while Making the Future Attractive

J. Conway, IHI

- Organising the system around patient and family
- Optimising the patient experience
- Staff satisfaction
- Patient activation and self-management

IT IS THE RIGHT THING TO DO!

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The London Declaration - a vision statement for Patients for Patient Safety, written at 1st PFPS workshop by patients and families from every region of WHO

We patients for patient safety will be the voice for all people but especially those who are now unheard. Together as partners, we ill collaborate in:

- Devising and promoting programmes for patients safety and patient empowerment
- Developing and driving a constructive dialogue with all partners concerned with patient safety
- Establishing systems for reporting and dealing with healthcare harm
- Defining best practices in dealing with harm and promoting those practices, e.g. IHI White Paper 'Respectful Management of Serious Clinical Events – What's your Crisis Management Plan?

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FRAMEWORK AND PROCESS

Report Safety First 2006

Irish Commission on Patient Safety & Quality Assurance 2010

"Knowledgeable Patients receiving safe & effective care from skilled professionals in appropriate environments with assessed outcomes"

"No one is ever hesitant to speak up regarding the well being of a patient and everyone has a high degree of confidence that their concern will be heard respectfully and acted upon"

- M. Leonard, Kaiser Permanente

COMMITMENT

- Proactive engagement of patients in own care
- Capture lessons learned from the patient experience
- Embed patient and family in every aspect of healthcare

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EFFECTING CHANGE
The Story and the Experience

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

-Indian Proverb

"Facts do not change feelings.....

- Vera Keane

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THE REALITY

Persistent back pain – GP Visits, X-Rays
Orthopaedic Surgeon – Bone Scan, Blood Tests

		1997	1999
•Calcium	3.51	(2.05-2.75)	5.73 (6.1)
	Described as 'inconsistent with life'.		
•Creatinine	141	(60-120)	214
•Urate	551	(120-480)	685
•Bilirubin Direct	9.9	(0-6)	
•Alk Phosphate	489	(90-300)	

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Every Point of Contact Failed Him...

Research
96% Success Rate;
1% Complication Rate

Peer Review

"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"

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

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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

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SHORTCOMINGS Contd.

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

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Disclosure

- Disclosure = ?
- Blame vs Integrity and Professionalism
- Learning? Preventing recurrence?
- Having the past inform the present while influencing the future
- The value of partnership
- Empowerment of patient and family by enablers within the system

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The Lived Experience

- Initial humane reactions
- Damage limitation
- Defensiveness, Closing ranks, lame excuses, muddying the waters
- Attempts to shift responsibility

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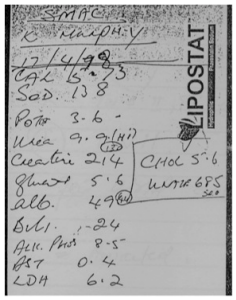
Inappropriate Responses and The Post-it Note

Confidence in ascertaining the truth shattered



Forced to reluctantly pursue the litigation route

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Court Ruling

"It is very clear to me that Kevin Murphy should not have died."

Judge Roderick Murphy at High Court Ruling
May 2004

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Adverse Events and Healthcare Staffs???

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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

ACKNOWLEDGE ERROR AND ALLOW LEARNING TO OCCUR

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A WISH LIST Contd.

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

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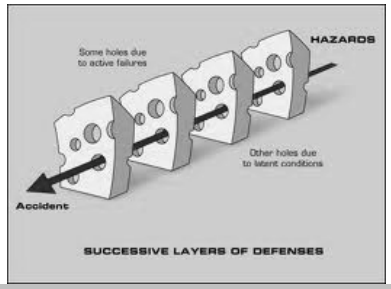
A Better Way – Invitation & Response

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



The Swiss Cheese Model

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A Personal Experience
'Nothing About Us Without Us'

- International, National, Local
- Invitation and Opportunity
- Leadership and Innovation

There is one thing worse than being blind and that is having sight but no vision

Helen Keller

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The Effectiveness of the Story
Examples from Healthcare Professionals and Students

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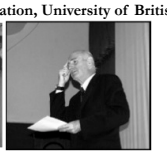
A Research Perspective and the WHO Curriculum Guide

Where's the Patients' Voice in Health Professional Education?

Christine Farrell, Angela Towle, William Godolphin

Division of Healthcare Communication, University of British Columbia

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THE WAY FORWARD

- Individual and corporate commitment to a just culture.
- Leadership as key to ensuring appropriate systems and supports are in place and sufficiently robust to enable delivery of safe care

Issues Requiring Resolution

- Communication
- Viewing Patient holistically
- Family Advocacy
- Experience vs Tunnel Vision
- Patient as Partner
- Danger times in patient journey
- Care Team
- Professionalism and Integrity
- Supports for Patients, Family and Clinicians - adverse events

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Other Insights

The time is Now

If health and/or healthcare is on the table, then the consumer (public, patient, family member) must be at the table, every table. **NOW**. -Lucian Leape

Demonstrating the courage to partner with challenging patients
-Pearls of Great Price? –
=
Making the Future Attractive

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PFPS and LESSONS LEARNED
- Partnership and Engagement -

- It is the right thing to do
- It works
- It benefits healthcare at all levels
- It benefits all partners
- It addresses the dilemma of how to bring it about
- The value of the WHO linkage
- Identifies challenge of translating aspiration to reality

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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

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

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"To err is human,
to cover up is unforgivable,
but to fail to learn is inexcusable."
-Sir Liam Donaldson,Chair, WHO Patient Safety

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Coming Soon

24 January INFECTION PREVENTION AND SOCIAL CHANGE
Speaker: Prof. Elaine Larson, Columbia University

06 February *(WHO Teleclass Teleclass)* IMPROVING THE PATIENT SAFETY CULTURE AS A SUCCESSFUL COMPONENT OF INFECTION CONTROL STRATEGIES
Speaker: Dr. Benedetta Allegranzi, WHO Patient Safety Challenge

07 February WHY EVIDENCE SHOULD HAVE BIOLOGICAL PLAUSIBILITY: THE STORY OF CHLORHEXIDINE AND ITS ROLE IN SKIN ANTISEPSIS
Speaker: Prof. Mathias Maiwald, National University of Singapore

12 February *(British Teleclass)* COMMISSIONING INFECTION PREVENTION & CONTROL SERVICES IN THE NEW NHS
Speaker: Debbie King, NHS Nolihull Clinical Commissioning Group

13 February *(South Pacific Teleclass)* HOSPITAL DESIGN AND INFECTION PREVENTION AND CONTROL

www.webbertraining.com/schedulep1.php

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