Third Global Ministerial Summit on Patient Safety
Panel Discussion 1 Patient Safety Culture

Positive Impact on Patient Engagement

-What I Have Undergone as a Bereaved Family-

Ikuko Toyoda

Director of Patient Safety Office,
IMS Rehabilitation Center Tokyo, Katsushika General Hospital

Chairman of NPO "Kakehashi (Bridge)",
-connecting patients, families and medical staff

April 13, 2018

My Son's pathology from Initial Consultation to Death

<Initial Visit for Medical Consultation>

Emergency room → Treatment (enema) → Home →Symptom become severe

<2nd Visit for Medical Consultation>

Return to Clinic (waited more than 20 minutes) → Examinations (X-ray, CT) → Treatment (enema) → Examinations (blood collection) → Infusion → Blood test result (waited for approximately 2 hours) → Hospital admission → Vomited blood / CPA approx. 2 hours later without physician's visit to the ward → Code Blue (emergency medical treatment) → Confirmed Death

Onset of disease / Hospital visit

⇨ Admission ⇨ Sudden death

a month later, there was

a sudden notice

A whistle-blower reported to several newspaper companies

↓

Medical record disclosure

→The hospital explained:

“We did our best.”

↓

Media Coverage

Newspaper Coverage of the Medical Malpractice of My Son

再三訴え やっと診察 その後数時間診ず

腸閉塞を放置 男児死亡

腹パンパン 顔真っ青

医師「待たせといて」

The Asahi Shimbun (newspaper)
Morning Edition on June 1, 2003

Road to the Establishment of the Medical Accident Investigation System

January 11, 1999	Accidental mix-up of patients undergoing surgery (Yokohama City University Hospital)
February 11, 1999	Infusion of the wrong drug (Tokyo Metropolitan Hiroo Hospital)
March 2001	Declaired to be the "Year to Promote Medical Safety" and recommendation "Coalition of Healthcare Professionals to enhance Patient Safety"
April 2001	Establishment of the Medical Safety Promotion Office, MHLW
March 9, 2003	Sudden death of my son (Riki) due to medical accident
September 2003	Jikei University School of Medicine Aoto Hospital Incident
April 2004	Supreme Court decision on the Tokyo Metropolitan Hiroo Hospital. "Article 21 of the Medical Practitioners Act"
April 2004	Joint statement of Japanese Society of Internal Medicine, the Japan Surgical Society, the Japanese Society of Pathology, and the Japanese Association of Medical Sciences "Notification of Medical Practice-related Patient Deaths ~ Toward the Establishment of a Neutral Specialized Agency ~"

Accommodation with the Hospital and Onwards

January 2004:	Reported the incident to police.
September 2005:	Settled with the hospital.
October 2006:	Court finalized a decision not to charge the attending doctor.

"Medical Safety Promotion Week" was established in the hospital, the week falls on before and after the anniversary date of my son's death. The hospital organizes a training seminar for medical safety every year on the week.

Change in feelings against the hospital —

Nurse's apology on the third year anniversary of death

Lecture was given by the bereaved family in the seminar in 2007

(A face-to-face dialogue between the bereaved family and the hospital staff realized for the first time, which led to a good relationship.)

“Our mission is to disclose information and think together”

Shinkatsushika Hospital, located in Katsushika-ku, Tokyo, with 176 beds

Yoichi Shimizu (became Hospital Director in 1999, Cardiology)

▼“The hospital director is responsible for medical safety.”
▼“Patients are ultimately asked to participate.”
▼“To hide one lie, thousands of other lies are necessary, and consequently, those concernedmay become defiant.”
▼“I may also turn around, depending on the circumstances. That’s why I need Ms. Toyoda to oversee us.”

Ikuko Toyoda (employed in 2004, Safety Manager)

▼Lost her son (Riki-chan; at the age of 5) in March 2003.
Misdiagnosis and handoff error　Cover-ups
▼“There should be no more victims or second victims. I don’t want anyone else to
suffer as I did.”

支・え・る きもち

情報開示し共に考える

「うそをつかない医療が私の理念です。そして、病院改革を患者さんに委ねていくことがよい経営につながると確信しています」

患者参加の病院改革を進める 清水 陽一さん 55
（新葛飾病院院長）

NPO法人「患者のための医療ネット」の事務所で、医療事故の被害者たちと話し込む清水陽一病院長。「悲劇から学ぶことが医療安全の基本」と言う―鈴木毅彦撮影

医療事故訴訟の鑑定書　事故原因などについて専門医が見解を示した文書。民事訴訟では、患者側鑑定、病院側鑑定に加え、裁判所が第三者の医師に依頼する鑑定もある。鑑定人のなり手の少なさが訴訟の長期化にもつながっている。

新葛飾病院のホームページは、http://www.shinkatsu-hp.com/
清水医師が参加するNPO法人「患者のための医療ネット（PMネット）」は、http://www.pm-net.jp/

Yomiuri Newspaper dated August 3, 2004

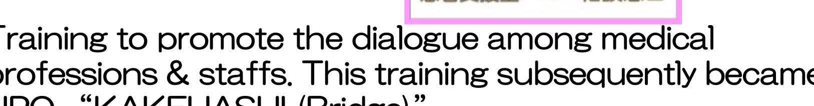
Shinkatsushika hospital (at that time)

Patient Support Office
Medical Safety Management Office

【 Full-time 】 One medical safety manager

【 Full-time 】 One medical dialogue faci litator

【Interlocking】 Nurse ・ MSW ・ Medical Division



Training to promote the dialogue among medical professions & staffs. This training subsequently became NPO "KAKEHASHI (Bridge)"

【 Where the patients and family support office locates】

1st floor, management building: in "Body Learning Center.

【Patient Councelling Counter: Library Hours】 Mon-Fri: 9:00 to 17:00

Sat: 9:00 to 12:00 *except holidays and Sundays

※ We have comment boxes in hospitals / clinics

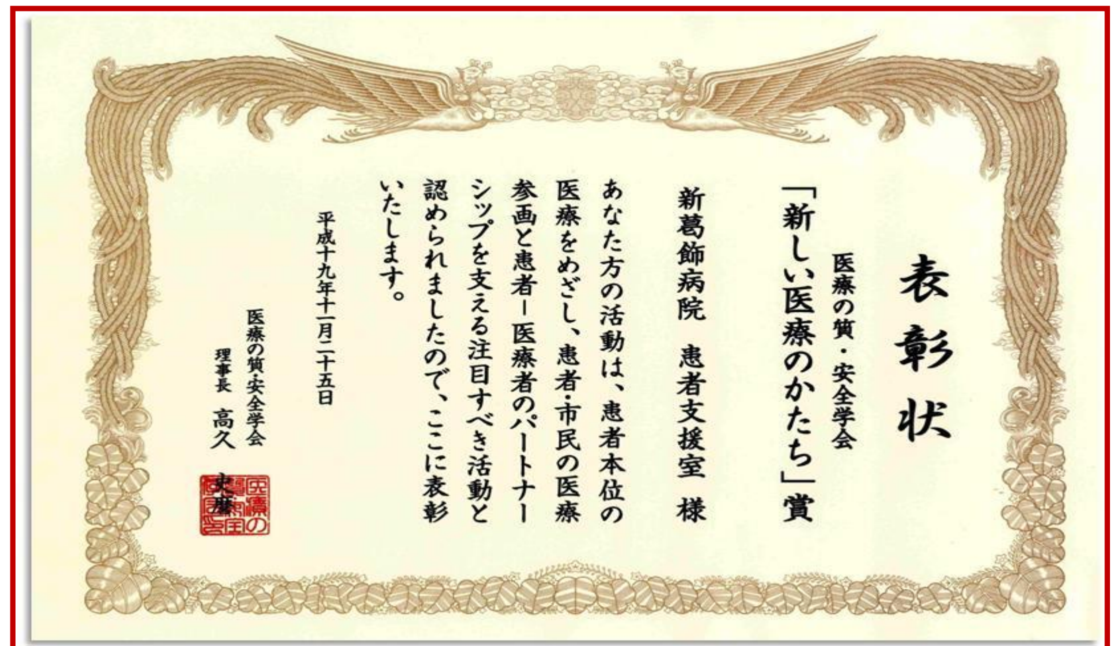
Answers are posted on the notice board

(We also support staffs)

Importance of face-to face talk

- Listen to the voice of the patients (listen)
- Sympathize (imagine)
- Make an effort to have a dialogue (Communication)

Received the first "a New Form of Healthcare"



表彰状

医療の質・安全学会
「新しい医療のかたち」賞

新葛飾病院 患者支援室 様

あなた方の活動は、患者本位の医療をめざし、患者・市民の医療参画と患者ー医療者のパートナーシップを支える注目すべき活動と認められましたので、ここに表彰いたします。

平成十九年十一月二十五日

医療の質・安全学会
理事長 高久 史麿

November 25, 2007

Sponsorship

Ministry of Health, Labour and Welfare, Ministry of Education, Culture, Sports, Science & Technology, Science Council Japan, All Japan Hospital Association, Japan Medical Association, Japan Nursing Association, Japan Dental Association, Japan Pharmaceutical Association, Japanese Society of Hospital Pharmacists, The Japan Association of Radiological Technologists, Japanese Association of Medical Technologists, Japan Council for Quality Health Care, The Japanese Society for Quality Control

Road to Establish a Medical Accident Investigation System

April 20, 2007 to December 1, 2008

"Panel on method for investigating deaths associated with medical treatment" - meeting were held 17 times

October 2007 MHLW "Proposal Draft for investigating deaths associated with medical treatment – Second Draft Proposal"

December 2007 Panel on Medical Dispute Solution "System for Identifying Causes of Medical Practice Related Deaths" Organized by Liberal Democratic Party

April 2008 MHLW released the "Proposal Draft for Identification of Causes of Deaths Resulting from Medical Accidents and Prevention of Recurrence for Medical Safety Assurance – Third Draft –" (asking for public comments).

June 2008 **MHLW "Outline of the Bill to Set up a Medical Safety Investigation Committee (provisional title)"**

Road to Establish a Medical Accident Investigation System

June 2008 Democratic Party of Japan “Draft Proposal for the Bill to Partially Revise the Medical Service Act etc. for the Provision of Information on Medical Care, Promotion of Counseling/Support and Proper Solution of Medical Disputes, and Prevention of Recurrence of Medical Accidents etc. (provisional title)” (commonly called “Patient Support Act Bill”), “System for Identifying Causes of Deaths (including Disability) Resulting from Medical Accidents etc. (Draft)”

August 2008 Established the “Medical Safety Liaison Council from the Patient’s Perspective.”

December 2008 Started distribution of leaflets and a campaign to collect signatures for the “Desire for Early Establishment of a Medical Accident Investigation Agency.”

October 2008 Worked on compiling “Major Opinions Received on the Third Draft Proposal and Draft Outline and Current Opinion of the MHLW.”

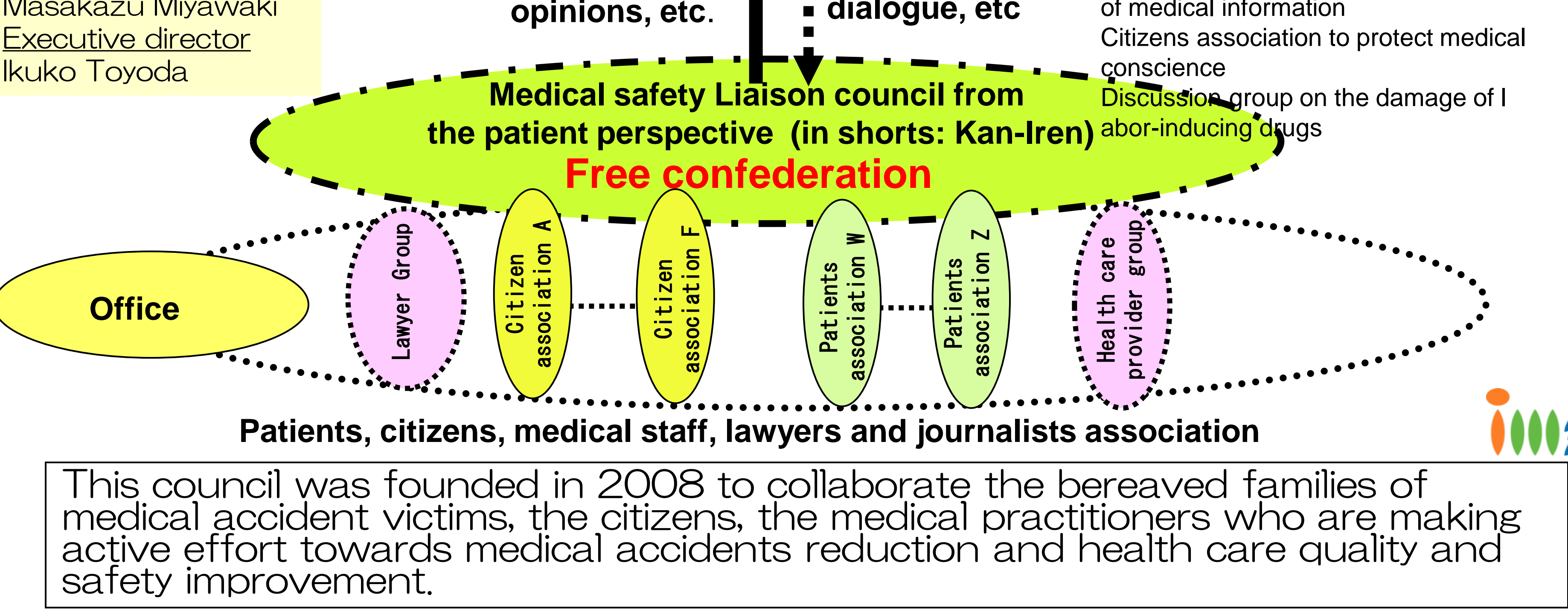
January 2009 Started operation of the “Obstetric Medical Compensation System.”

Medical safety Liaison council from the patient perspective (Kan-I ren)

HP ; http://kan-iren.txt-nifty.com/top/

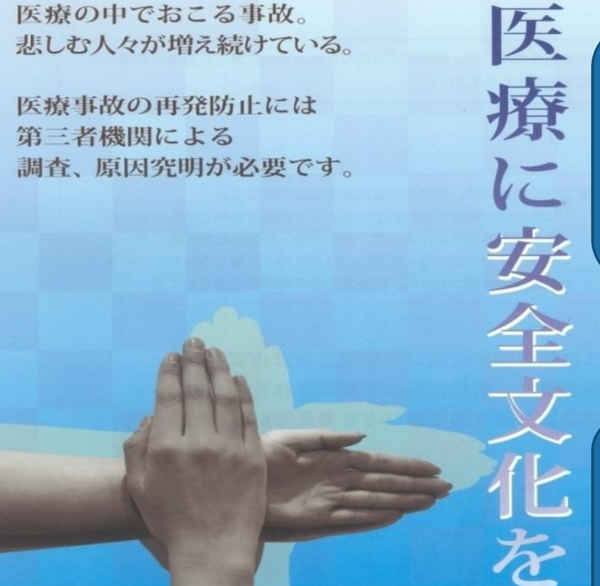
President
Hiroyuki Nagai
Vice President
Sugamata Hiromichi
Masakazu Miyawaki
Executive director
Ikuko Toyoda

Members of the council
Association of medical malpractice plaintiff,
Citizen ombudsman medio of medical accidents
Citizens association seeking public disclosure of medical information
Citizens association to protect medical conscience
Discussion group on the damage of l abor-inducing drugs



This council was founded in 2008 to collaborate the bereaved families of medical accident victims, the citizens, the medical practitioners who are making active effort towards medical accidents reduction and health care quality and safety improvement.

Campaign for early establishment of medical accident investigation agency



毎日新聞 2018年（平成30年）4月4日（水） D朝刊 社会 30

医療事故 防ぎたい

遺族ら署名 10年100回

医療事故の遺族らでつくる「医療版事故調推進フォーラム」が、公正な事故調査制度の実現を求めて10年前から毎月続けてきた街頭署名が、8日に100回を迎える。活動は2015年の制度発足の原動力になったが、運用を巡る課題も多い。遺族たちは「被害者の一番の願いは、事故を再発防止につなげること。そのために今後も活動を続けなければ」と力を込める。【熊谷豪、写真も】

届け出低調「制度改善を」

想定以下 2年で857件

事故の報告件数: 2015年（10〜12月）; 16（1〜12） 406; 17（1〜12） 370
※日本医療安全調査機構による

医療事故調査制度の改善を求めてチラシを配る遺族ら。この日が99回目の街頭署名活動だった＝東京都品川区で3月17日

“Bereaved families collected signatures 100 times in ten years”

“Strong hope to Prevent Medical Accidents”

The Mainichi Newspaper 4th April,2018

Activities Undertaken so far to Establish a Medical Accident Investigation System

March 2010 **Established the "Liaison and Adjustment Council of Agencies for Alternative Medical Dispute Resolution (ADR)."**

June 2010 Established the "Panel on Autopsy Imaging that Contributes to the Identification of the Cause of Death." - July 2010 Submitted the report.

August 2011 Established the "Panel on No-fault Compensation System that Contributes to Improvement of Health Service Quality."

February 15, 2012 to May 29, 2013

"Panel on Medical Accident Investigation System" - 13 meetings were held.

May 2013 **MHLW "Discussions on Basic Policy for Medical Accident Investigation System "**

Symposium to Establish the NPO “Kakehashi(Bridge)”

May 27, 2012

2012年（平成24年）5月25日（金）夕刊 毎日新聞

医療現場に信頼を

事故被害者と医師らNPO

(Photographed by Ms. Yasuko Jinbo)

The Mainichi Newspaper (May 25, 2012)

NPO Corporation "Bridge (Kakehashi)"
Bridging Patients/Families and Health Care

◆With the aim of building a mutual trust relationship between medical staff and patients/family, we provide support and enlightenment to medical staff to facilitate communication and dialogue.
◆By learning from the feelings of patients/family members who encountered medical accidents, we contribute to the improvement of the future medical safety and quality.
◆patients/family members who encountered medical accidents and involved people provide opportunities for healthcare professionals and citizens to think about the importance of dialogue between patients/family and related persons to restore the post-accident mutual trust relationship.

< Background >

May 2006: Started workshops aiming to facilitate dialogue between staffs in Shinkatsushika Hospital.
September 2008: Due to the needs, we established "Kakehashi(Bridge) Study Group for Dialogues Leading to the Trust Relationship with Patients/Family" and expanded the workshops outside the hospital.
2011: Conducted workshops to train patient-supporting staff (in-hospital supporting staff) in Tokyo, Osaka, and Sapporo.
April 2012: Established the NPO Corporation with the focus on education projects for training of medical dialogue facilitators.
*April 2012: During the revision of the medical service fees, an additional incentive for a well-organized patient support system was adopted.

Well-organized Patient Support System
(Additional incentive for a well-organized patient support system: From April 2012)

I. Guideline for Medical Dialogue Facilitators

1. Positioning of medical dialogue facilitators at medical institutions

A medical dialogue facilitator is authorized by the supervisor of each medical institution to serve as a person who plays a role in coordinating the patient/family support system and facilitating dialogue between the persons involved, and responds to inquiries/consultations etc. from the patient/family systematically in collaboration with the medical safety manager, each department of medical services, and administrative departments based on the instructions of the supervisor.

I. Operating Guideline for Medical Dialogue Facilitators (Health and Labour Sciences Special Research Project 2012)

Medical dialogue facilitators training by NPO bridge

Director, lecturer members

At Ms. Sorrel King's house (Baltimore)

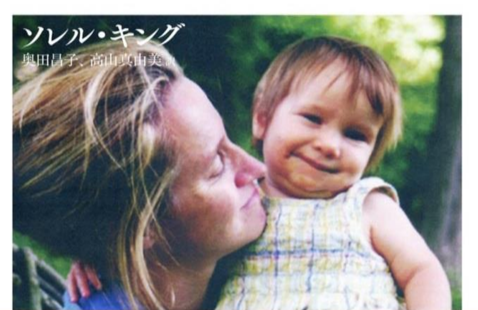
May 9, 2008

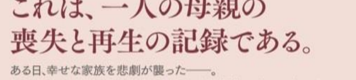
At the Josie King Foundation office

Patient stories, rather than data, are considered to have significant meaning in the US medical setting.

ジョージィの物語

小さな女の子の死が医療にもたらした大きな変化





ある日、幸せな家族を悲劇が襲った——。
世界トップクラスの病院で治療を受けた1歳半のジョージィが、
医療事故で命を奪われたのだ。
娘の死を受け入れられない母ソレル。
病院との対立、夫婦の危機、苦悩と葛藤……
絶望の底に沈んだ彼女だったが、同じ悲劇があまりにも多い現実を知り、
医療の安全を目指して立ちあがる。
改革に身を捧げる医師と看護師たち、思いをともにする無数の患者と家族たち。
多くの協力者と出会い一歩ずつ進むなかでソレルが見いだしたものとは……。

「世界を変える50人の女性」に選ばれた著者が贈る渾身のメッセージ。

英治出版

Ms. Sorrel King's book titled "Josie's Story" [Eiji Press]

From 2009

National Hospital Organization

Kanto Shinetsu Group Seminars for Training of Supervisory Doctors

"Communication Education Aimed for Patient Safety"

IMS Rehabilitation Center Tokyo, Katsushika General Hospital
Workshop Co-sponsored by the World Health Organization (WHO)
Quality of Medical Care at Hospitals and Patient Safety Management Course
Held every March from 2016
葛飾ロイヤルケアセンター
地域包括支援センター堀切
At Katsushika Royal Care Center, Shinkatsushika Royal Clinic

Scenery of the coursework

From 2017
Curriculum of the Department of Medicine, International University of Health and Welfare

◆ Medical Professionalism I (Basic)
First-year: Medical Ethics and Medical Safety

Participation of Patients/Family (Bereaved Family)

Hisashi Katsumura

Member in charge of Arrangement/Administration/Recurrence Prevention for the Obstetric Medical Compensation System

Hiroyuki Nagai

Member in charge of Administration, Medical Accident Investigation/Support Center, Medical Accident Investigation System

Masakazu Miyawaki

Member of the Liaison and Adjustment Council of Agencies for Alternative Medical Dispute Resolution (ADR)

Ikuko Toyoda

Member of the Cause Analysis Committee, Obstetric Medical Compensation System

Member of the General Research Committee, Medical Accident Investigation/Support Center, Medical Accident Investigation System

Junko Kitada

Member of the Cause Analysis Committee, Obstetric Medical Compensation System

Ayako Kawada

Expert Advisor for the Obstetric Medical Compensation System

Seven Things That Should Be Kept in Mind by Medical Dialogue Facilitators

1. Stay in touch with the pain/suffering of involved persons with empathy

Malpractice deeply hurts the feelings of patients/family and healthcare providers.

Medical dialogue facilitators therefore have to consider the feelings of persons involved to the greatest extent.

2. Listen to stories of involved persons and think together

Medical dialogue facilitators should first devote their full attention to “listening” to understand the feelings of persons involved.

They should then support the patients/family and healthcare providers, and think together about what they are going to do, rather than giving proposals and/or advice.

3. Sincerely respect the patients, their family, and healthcare providers

What is important for medical dialogue facilitators is to sincerely respect and try to understand the feelings of patients/family and healthcare providers. Medical dialogue facilitators should not control their feelings. It is necessary to undergo training to acquire such skills, but the final result should not be copybook skills (listening and/or paraphrasing techniques).

Seven Things That Should Be Kept in Mind by Medical Dialogue Facilitators

4. Try not to cover others' roles but help them to face the facts

Medical dialogue facilitators should not stand in for "victims/victimizers," e.g., offer an apology on someone's behalf.

What medical dialogue facilitators need to do is to help patients/family and healthcare providers face the fact and organize an environment that makes it possible for them.

5. Act beyond an "impartial/neutral" position

Being neutral is a measure to gain trust from patients/family and healthcare providers; however, hospital staff may not seem to be "impartial/neutral" on some occasions. Medical dialogue facilitators have to build a trust relationship by remaining on the side of the sufferers depending on the situation.

6. Not getting involved in, but work together on the investigation of malpractice analysis

Medical dialogue facilitators should not get directly involved in the investigation of the malpractice analysis but have to collaborate appropriately.

7. Gain a small trust to grow into a big trust

There is no single correct answer or measure to deal with malpractice once it has occurred. Medical dialogue facilitators then need to help build a process whereby a small trust can be gained and then grown into a big trust through truthful dialogues between patients/family and healthcare providers.