



A SYNOPSIS OF GUIDELINES ON SHARING SIGNIFICANT INFORMATION IN HEALTHCARE SETTINGS

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FOREWORD

Training in communication and providing information to patients and their families in a caring and compassionate manner is part and parcel of the training received by health care providers in their formative years. It is imperative that this be reinforced and enhanced throughout their professional careers. However, there is very little opportunity for such systematic reinforcement and most continuing professional development programmes pay little attention to this aspect.

This vacuum was highlighted in the presentations made at the symposium titled “Towards a better tomorrow for people with Down Syndrome” which was organised by the Expert Committee on Disability of the Sri Lanka Medical Association, in collaboration with the Sri Lanka College of Paediatricians to mark World Down Syndrome Day. Subsequently, these deficiencies were discussed at a Council Meeting of the Sri Lanka Medical Association and a committee was appointed to develop a booklet providing general guidance on communication and providing sensitive information to patients and their relatives by health care providers.

I wish to congratulate the committee for developing this booklet in such a short period of time. I am quite sure that it would make useful reading to all medical professionals and it would help them to develop satisfactory communication procedures with their patients.

I hope that the booklet will be translated into Sinhala and Tamil in the future so that it would become a useful handbook for all health care providers in the field.

Professor Vajira H. W. Dissanayake
President, Sri Lanka Medical Association

21st December 2012

SOME BASIC THOUGHTS ON COMMUNICATION

Communication is not a one-way process. It includes two or more people and is a blend of listening, comprehension and verbal or non-verbal responses. What we hear and say are of the utmost importance. In most situations related to health care it is essential that a certain degree of empathy and compassion are incorporated into the entire procedure. Respect for patients, ensuring privacy and talking to them in a manner that is acceptable, are virtues that are an integral part of good communication strategies.

It was Hippocrates, the great medical philosopher, who said that the duty of the medical professionals is to cure sometimes, relieve often and comfort always. In that context, communication is an integral part of the composite venture. It is an extremely important procedure for all medical and allied professionals and communication with patients and their relatives is a process that is applicable to all levels of medical professionals. It should not be taken lightly and care needs to be taken to develop good communication practices.

Chapter 1. INTRODUCTION

KEY POINTS

- Being provided with sensitive information in a clear, satisfactory and humane way is a patient's right.
- Communicating with a patient or a relative may involve day-to-day conversations as well as special encounters where dedicated time has to be set apart for provision of sensitive information.
- The ways in which one communicates with a patient, including the provision of privacy, use of language, gestures used and even body language, are crucial.
- Establishment of good rapport and a healthy relationship with the patient and the relatives would be beneficial to all concerned.
- Such a relationship would help to discourage potential litigation as well.

There have been many anecdotal reports presented, specific instances quoted, and, considerable concerns expressed in many quarters, regarding problems that have arisen as a result of unsatisfactory communication of information by healthcare workers to patients and their relatives. There may be all kinds of mitigating circumstances that could account for the occurrence of these problems but it must be acknowledged that it is essential to provide adequate and proper information to patients and their relatives as and when the need arises. In certain situations where the information is of a sensitive or potentially disturbing nature, particular care needs to be taken to convey the information in an appropriate manner.

Towards that end, The Sri Lanka Medical Association (SLMA) has decided to take steps to formulate some basic strategies to be followed by healthcare workers in communicating with patients.

There are quite a few situations in which information has to be conveyed to patients and their relatives. These can have a very wide range. Some, but not all of it, may include :-

- Day-to-day conversations regarding progress of a patient, with the patient as well as with the relatives.
- Obtaining consent for investigations, procedures, surgery, research etc.
- Breaking sensitive or potentially disturbing news.
- Detailing the intricacies of prognosis.
- Providing information regarding follow-up in an out-patient setting.

It must be emphasised at the outset that obtaining information, especially in a simple, humanitarian and compassionate way, is within the scheme of patients' and their relatives' rights. All healthcare workers and especially the doctors dealing with patients, need to take cognisance of this axiom at all times. It is also a privilege and a courtesy that we are duty bound to extend to our patients.

The way in which information is provided and patients' questions and concerns are addressed is crucial to developing trust and a good rapport with the patients

and their relatives. In addition to the information provided, the setting in which it is done is also of paramount importance. It is essential to take steps to ensure privacy of the entire enterprise and a comfortable scenario has to be arranged for this purpose. A humane and empathetic approach is vital towards establishing that all important and trustworthy relationship with the patients and their relatives. Time spent in such an endeavour is time well spent as the outcome is likely to be mutually beneficial. Honesty on the part of the information provider is extremely important in these efforts. Everybody, even the patients and relatives, recognise the fact that it is not always possible to provide clear-cut answers to all their queries and worries. One may need to ask for time to check some details and get back to the patient and the relatives. This in no way diminishes the respect and trust that the patient and relatives have in the health care worker. In fact, such honest practices, very often augment the regard that the patient and the relatives have for the health care worker. In general, it is always much better to give our patients a bit of our hearts than a piece of our minds.

It is generally in order for junior and middle grade medical officers to deal with standard conditions and uncomplicated clinical problems. However, it is advocated that the most senior member of a team deals with complex and complicated clinical situations, including breaking sensitive and potentially disturbing news as well as diagnoses and prognosis of conditions that may have significant uncertainties associated with them.

Once a good rapport is built up with the patient and the relatives, there will not be any animosity even if things go wrong due to unavoidable human error. Good communication and adequate explanations given to patients and their relatives would go a long way towards preventing litigation against healthcare workers.

Many people will think twice or even thrice before suing a health care worker whom they have trusted, had a good working relationship with, and perhaps even admired for his or her capabilities.

This venture on communication by the SLMA is envisaged to provide a framework and some guidance to healthcare workers on the intricacies of providing information as well as communicating with patients and their relatives. It is by no means a comprehensive “bible” of how things have to be done. Many improvisations may need to be undertaken depending on the circumstances involved. Direct translations of words given as examples in this booklet may not always be appropriate and suitable similar words or phrases would need to be used. This would also need to take into account the education and the social standing of the patient and relatives.

However, one needs to recognise the essential requirements and the obvious desirability of a fruitful dialogue with our patients and their relatives as a *sine qua non* for a lasting and healthy relationship with our clients. It is perhaps true to say that all communication problems arise because we do not listen to understand but we tend to listen to reply. We do need to understand our patients, take note of what they say and try to gauge what they need.

Chapter 2. A COMMUNICATION PROTOCOL

KEY POINTS

- The E-C-D- Model consists of **E**nvironment, **C**ommunication and **D**ocumentation
- Each of these have several key aspects
- All three components are equally important
- These contribute to patient satisfaction

The following general protocol or features need to be considered in a communication scenario.

There are several areas that are important to consider. The ***E-C-D Model*** is the most commonly used one. This consists of :-

- **E**nvironmental aspects
- **C**ommunication
- **D**ocumentation

Each consists of several components.

Environmental aspects

This is to recognize the importance of where the communication takes place. There should be adequate privacy (at least a covered area with a place to sit), and physical barriers (such as large tables) between the health professional and patient / relatives should be minimized and adequate time available to share information. In some instances, a chaperone is necessary. In certain countries, protocols are in place that ensure 2 or more health care workers are present at the time of the discussion.

Communication

The communication itself could be structured under several sub-headings.

- Greeting / Introduction : A culturally appropriate greeting should be used.
- Building rapport : A few open ended questions to 'break the ice'.
- Finding out what is known. This offers a platform for the health care worker to build-on.
- Exploring the areas that need to be shared.
- Allowing time for further questions and clarifications.
- Agreeing as to what was understood.
- Providing information on whom to contact and how to contact that person in the team again or how to obtain further information.
- Closing session

The language, the speed of conversation and the dialect used by the health professionals are crucial. Please ensure that you speak slowly. Choose your words carefully because patients and relatives may remember one or two crucial words or a sentence, and may misinterpret or misunderstand your sentence.

The importance of non-verbal cues such as the body language and tone of voice must be appreciated. This is especially relevant in our Sri Lankan culture. The gestures in communication, the posture assumed when speaking to a person, standing up from the seat to speak to an elderly person or clergy, are some examples.

The entire communication process must be undertaken slowly with adequate time given for the patients and carers to digest the information.

Documentation

It is very important to note and write down some details of what was discussed, at least as a brief statement. These are measures for future reference and also perhaps to avoid disputes that may arise as a result of complaints or litigation where the hospital or clinic is accused of not informing the patient or guardian.

It must be stressed that these are basic steps that help to build patient confidence and satisfaction regarding the entire process. By adhering to these fundamentals many subsequent problems could be avoided and they would induce patient confidence on the attending doctor.

Chapter 3. ETHICS OF SHARING SIGNIFICANT INFORMATION

KEY POINTS

- Ethics play a major role in all communication procedures.
- Ethical behaviour on the part of the communicator has many components such as patient autonomy, respect, consent, privacy, confidentiality etc.
- A doctor is duty bound to adhere to these ethical principles in sharing sensitive information with the patients and their families.

It is unethical to disclose significant information by an unskilled person because it is a complex communication task and may create misunderstanding of the condition concerned. What is recommended is a face-to-face discussion handled by the most senior responsible and available doctor.

It is unethical to share significant information without having adequate knowledge of the condition, alternative management strategies and prognosis. Familiarise yourself with the patient's background, medical history, investigations and management options.

It could sometimes be ethical to withhold some information because it is believed to be in the best interest of the patient. This may be especially so in cases where there is a history of psychological problems or psychiatric illness.

Eq. 1: A 35 year old woman presents with a breast lump to the surgical clinic because her mother died few months back due to a malignancy. She is still grieving the loss. You are certain that this lump has many features suggestive of a carcinoma. In this instance, you need not reveal your suspected diagnosis to the patient till you have confirmed the diagnosis with a biopsy report.

Eq.2 : A 45 year old man is clinically confirmed to have Dengue Haemorrhagic Fever. His son too is critically ill in the ICU with DHF. The father's platelets are dropping rapidly. In this situation, it is not essential to volunteer and reveal this fact to the son.

Patient autonomy

- Patient should be allowed to be accompanied by another person such as a family member, friend or another relative.
- Respect

Use of understandable language, according to their educational level, prior knowledge of the condition being discussed, assessment of psychosocial background, sensitivity, respect for their beliefs, religions, cultural differences, family support and follow up should all be included in demonstrating respect for the patient.

If it is a child, both the child and parents should be included and the child kept with the parents.

One must respect the right of patients for a second opinion.

Telling the truth, transparency and honesty regarding current knowledge is very important to gain confidence of the patients and relatives.

It is essential to provide uniform and evidence-based information. One also needs to indicate the uncertainty of some of the evidence, if it is important and relevant.

Informed consent

Consent should always be obtained from the patient before disclosing significant information to a third party. In the case of children, as there is no definitive legal age of consent for this purpose in Sri Lanka, the educational level and maturity of the child needs to be taken into account before requesting such consent.

Privacy

Doctors must make sure that they respect the private and family lives of patients. Ideally an interview room needs to be used. In a situation where the patient is confined to bed, it is essential to pull the curtains around the bed or provide a mobile screen.

Confidentiality

It is unethical to disclose sensitive information to a third party without obtaining the consent of the patient. With respect to access to confidential information of a patient or a child who is educated and mature enough to understand the situation, disclosure of such details to a family member/relative/friend/child's parent or others, without written permission of the individual patient is unethical.

In the management of long-term or chronic disorders, it would be unethical to abstain from providing information on continuing care of the patient to the family doctor. If such information is deliberately withheld, one must have an important and compelling reason to do so.

Providing sensitive information in an unscrupulously ethical manner is a bounden duty of all doctors. It is the least that a patient would expect from a caring doctor.

Chapter 4. BREAKING SIGNIFICANT MEDICAL NEWS : A PATIENT'S PERSPECTIVE

KEY POINTS

- Conveying significant information is an important and significant task of a medical professional.
- It is most pertinent to consider the expectations of the patients in this regard.
- Being prepared, showing empathy and sensitivity, explaining details, answering the queries and being honest, are traits that are most desirable from a patient's perspective.
- Patients should not be made to look like "exhibits" and should not be referred to using potentially derogatory nomenclature.

Sharing significant medical news with a patient and members of his family is perhaps one of the most important and significant tasks that a Medical Professional will have to perform. Similarly, it is perhaps one of the most worrying and even intimidating experiences for the patient and his family.

Therefore, it would be prudent for a medical professional to pay serious attention to the expectations of a patient and his family, when breaking significant medical news to them. The following are some critical factors to be kept in mind when significant medical news is broken to them, though it is not meant to be an exhaustive list.

Be understanding and sensitive.

These situations are probably the worst situations the patient and his family may face in life. They may breakdown or become emotional. This is only to be expected. Such situations need to be handled with empathy, patience and tolerance.

Be prepared.

One needs to be quite sure of the medical history, the clinical situation and the diagnostic results relating to the patient, prior to breaking significant medical news. Also be prepared about the condition, treatment modalities and the options available for the patient. Any hesitation or wrong statement regarding medical history or diagnostic details will only create doubt in the mind of the patient and the family when significant medical news is broken to them.

Be ready to give time to the patient.

Significant medical news should not be broken to a patient hurriedly or impatiently. It will only aggravate their misery. Breaking such news will necessarily take time. Questions will be asked and explanations will be needed. After all,

significant medical news doesn't have to be broken to patients all the time. Therefore, when it needs to be done, the patient deserves the time and has a right to your time.

Be clear and avoid using complicated medical terms.

Please make sure that you explain the news in simple language that the patient and the family can understand. If complicated medical terms are used, the patient may not understand even the significance of what is said.

It may be necessary to ask questions to see whether the patient has understood what was said.

Explain the options available clearly.

This is important as the patient will be able to make an informed decision only if he or she is aware of the available options.

Where appropriate, explain what needs to be done to overcome, control or contain the situation clearly.

To a patient or the family, explaining what needs to be done is an essential part of significant medical news broken to them. For example, if a parent is told that the child is affected by Down Syndrome, the parent will want to know and needs to know how they should handle the child in the future and what the future hold for them. Otherwise, the news will probably mean the "end of their world".

Wherever possible, be positive and encouraging to the patient and the family without creating unnecessary hope or optimism. Do not be unduly pessimistic.

Allow the patient and the family to raise questions.

The patient and the family will have many questions arising from the news. Many of them could be anticipated. Be patient and provide clear answers.

Be honest – If you do not know any aspect that they have queried, tell them so.

No patient expects a medical professional to know everything about everything. Patients respect a medical professional who says that he will clarify a matter for them after researching. This also shows dedication and commitment on the part of the medical professional and in no way reduces the trust and regard the patient has for the medical professional.

However, please ensure that you have the information available during their next visit.

Where possible involve the patient (and where appropriate, the family) in decision making.

It is the patient's right to do so.

Be open to a patient's suggestions for a second opinion.

Do not be offended if a patient suggests this. Again, it is a right of the patient. Confirmation of the diagnosis and instructions already given will enhance the confidence of the patient in the medical professional.

Avoid allowing your personal beliefs and ideas to prejudice the care of the patient.

The patient is entitled to the care his condition demands. It would be inappropriate to make moral or ethical judgement relating to the patient based on the medical professional's personal beliefs. Particular care should be taken in refusing medical treatment and in life and death decisions.

Ensure that the support staff members treat the patient and the family with respect and dignity.

Patients spend more time with the support staff of a medical professional than with the professional himself or herself. It is essential that the staff members are trained to handle them respectfully in a manner which protects their dignity.

Labels (e.g.: -"Heart case", "Cancer patient", "VD patient", "HIV patient", "Down baby") should be avoided at all times.

The patients should not be treated by the support staff as "exhibits".

Chapter 5. COMMUNICATING SENSITIVE INFORMATION: SOME PRACTICAL ISSUES

KEY POINTS

- Conveying news of a sensitive nature is an integral part of being a doctor
- The process of conveying such news could be emotionally demanding
- Giving the news correctly will have an impact on how the people who receive it will relate to the new circumstances
- Efforts must be made to minimize delays in conveying the news
- The news must be conveyed clearly, with honest explanations. There must be no contradictions on what is conveyed between personnel
- Respect the dignity of the person and the family

Nobody likes to hear “bad news”. This makes conveying sensitive information, particularly of a potentially disturbing nature, an emotionally demanding task for the conveyor as well as the receiver. Giving sensitive information to patients and their loved ones is an integral part of being a Health Care Worker. However, since training in this area does not receive adequate attention in medical curricula, people either shy away from getting involved in giving such sensitive information, potentially bad news or deal with the procedure in an unsatisfactory manner.

What is sensitive information?

Often, sensitive information deals with an irreplaceable loss and/or having to make major adjustments in people’s lives to deal with a new set of circumstances. Some examples include an unexpected death during surgery, diagnosis of a degenerative condition that would invariably continue on a downward course, a malignancy or an unexpected major abnormality in a newborn baby.

The basic principles in breaking sensitive news

It is vitally important to give sensitive information in a proper way. How a person relates to the new situation would depend greatly on how the information is conveyed. For example, a family’s relationship with a baby with an anomaly could be affected profoundly and even irreversibly by giving information in an overly negative way. The ***SPIKES Protocol***, a well recognized guide for conveying sensitive information is referred to elsewhere in this book. This chapter aims to address its practicalities. It is important to remember that conveying information is not only dealing with the patient but also with other members of the family who are likely to be affected by the news.

The reaction

Denial is a natural reaction and a coping strategy. Therefore, one needs to be prepared for silence, tears and questions. It is common for parents to claim that a baby with Down syndrome is normal or for a mother carrying a dead baby to claim

she feels fetal movements. Blame is also a recognized part of the psychological reaction to receiving bad news. Blame may fall on a variety of people or circumstances, varying from one's own self to even the person breaking the news. Unfounded blame could be particularly harmful. Some may continue self-blame for years and this could have a major impact on adjusting to a loss. In other situations, other members of the family may place the blame on a patient or a spouse, affecting inter-relationships in that family.

The initiation

One of the most stressful and emotionally demanding parts of breaking sensitive news is the act of broaching the subject. How does one begin to tell a family waiting for news that the patient died due to an unexpected complication? How does one begin to tell a mother that the baby she is carrying has died in the womb, especially when she is least expecting it?

There is no easy way to begin to convey bad news. It is vitally important to minimize periods of uncertainty and to reach a conclusion with the least possible delay. For example, when the fetal heart is inaudible with a stethoscope, a final decision about the fetus' wellbeing must be determined using ultrasound at the earliest possible time. Times of uncertainty are extremely distressing and it is unfair to subject people to long periods of uncertainty.

The continuation

It is also impossible to generalize the practical aspects of conveying sensitive news since the realities are so variable. In the situation of having to convey a histopathology report that confirms a diagnosis of a cancer it will not need to be conveyed immediately, but sometime later into a consultation. However, someone who discovers a fetal anomaly during a routine ultrasound scan will not have the luxury of time. The situations are different in that one is somewhat prepared for the result having undergone a biopsy while the other person is one who is totally unprepared, expecting to hear nothing but good news. In the latter situation, it may be useful if the Health Care Worker could express concern non-verbally before initiating the process of conveying the news. This may take the form of studying the ultrasound picture intensely, but there must be the minimum of delay. When it becomes clear that the news that has to be conveyed is of a somewhat disturbing nature, it is prudent to familiarize oneself with the clinical records of the client. It is vital that questions from the patient or the family are answered unambiguously and honestly. It is better to admit ignorance or lack of knowledge rather than to be vague or to give wrong answers. It is also important to be prepared for the emotional reactions by those receiving the news.

People vary in their ability to absorb bad news and it is important to bear this in mind. The reactions vary according to different circumstances and the people receiving the news. Crying is a common reaction and it is important that time for this is allowed. It is quite usual for people to fail to grasp the information given in an initial discussion on sensitive information. However the information will be

important for consideration later or to convey the information to their social and family network. People who are given unpleasant news find notes and diagrams made during the interview to be quite useful to assimilate what has been said to them. Although the news is usually given to the people who are directly involved in the situation, there will be many in their social circles with whom they would want to share it. Sketches and notes will be of much use for them to discuss matters and to come to terms with the new situation. Even in the Sri Lankan scenario, a telephone number to seek clarifications is to be recommended.

One of the main issues of receiving significant information is how the recipients would need to adjust themselves to the new situation that has come about. This is particularly important in cases of a progressive disease or a permanent loss of function such as an amputation or the birth of a baby with an anomaly. Parents of an infant in whom Down syndrome has been diagnosed would want to know what the expectations for the child's development would be and how they could maximally exploit the child's potential and where they could obtain more information regarding these.

Sometimes, the person or people receiving the news could blame the person conveying the information for the loss or damage. It is prudent not to accept guilt in these situations. However, it is important to empathize and to respect the dignity of the person or people receiving the bad news.

Receiving contradictory messages is particularly painful for people receiving bad news. Consensus between personnel providing care on what must be conveyed could circumvent this.

Finally, it could be said that conveying sensitive information is an important part of being a Health Care Worker and a test of professionalism. It can be mentally draining, but nevertheless, conveying such news correctly will make a major difference to the way people relate to the new situation.

Chapter 6. DIAGNOSIS AND PROGNOSIS

KEY POINTS

- Diagnosis of a medical condition, however trivial it may be, has a major impact on the patient and his/her family
- The method/s of informing patient/family of the diagnosis and its prognosis should be considered a core competency for doctors.
- The six-step **SPIKES Protocol** is a suitable guide to follow.
- It provides an orderly format that is easy to understand and plan for the entire procedure of communicating sensitive information.

In the art of medical communication, diagnosis and prognosis are important factors which have an immediate, intermediate and long term impact on the patient, family, community, the doctor and the healthcare team or system. Hence the manner in which this essential medical information is communicated to the patient and or the family becomes an essential core competency for all healthcare personnel. Hippocrates wrote “*In the art of medicine there are three factors – the disease, the patient and the doctor..... It is not easy for the ordinary people to understand why they are ill or why they are better or worse, but if it is explained by someone else, it can seem quite a simple matter – if the doctor fails to make himself understood he may miss the truth of the illness*”. Informing patients and their families about accurate diagnosis and prognosis could sometimes be quite difficult. The 6-step SPIKES protocol is a useful tool in this process. It should not be used as a mandatory script but used as a guide in conveying the diagnosis and prognosis.

The 6-Step SPIKES Protocol

<u>S</u> etting.	1. Getting started
<u>P</u> erception.	2. What does the patient know?
<u>I</u> nvitation	3. How much does the patient want to know?
<u>K</u> nowledge	4. Share the information
<u>E</u> motion	5. Respond to feelings
<u>S</u> ubsequent	6. Plan next steps and follow up

Getting started

Familiarise yourself and confirm the medical *facts* of the case. One needs to plan beforehand what needs to be discussed. Please do not delegate the task of informing diagnosis and prognosis to someone who may not be quite competent in the procedure.

What does the patient know?

Establish what the patient and family know about the patient’s current condition or health status. One could use information available to ascertain whether the patient

and family will be able to comprehend the information. If the patient or the family members present are unable to comprehend the information, one needs to identify a suitable family member or friend who will be able to do so.

How much does the patient want to know?

People handle information differently, depending on their age, sex, race, ethnicity, culture, religion, level of education and socioeconomic status. Each patient has the right to voluntarily decline to receive any information and may designate someone else to communicate on his or her behalf. When the family says “don’t tell” important medical information to the patient, although the physician has a legal obligation to obtain informed consent from the patient, an effective therapeutic relationship requires a congenial alliance with the family. These factors must be respected. One needs to ask the patient and the family how they would like to receive the information.

Sharing the information

Consider the implications of the diagnostic and prognostic information you are about to provide to the patient

E.g. Patients who wish to plan their lives want information that is more detailed. Those who are terrified may do better with answers that are more general.

One has to deliver information in a sensitive but clear manner, keeping ‘medical jargon’ to a minimum. Do not minimize the severity of the situation. Well intentioned efforts to ‘soften the blow’ can lead to vagueness and confusion.

Respond to feelings

Patients and families respond in many different ways. The responses may be quite unpredictable.

However, one needs to reassure them that their responses are normal. Observe non-verbal communication of patient and family with particular interest being paid to facial expressions and body language. Consider touching the patient appropriately in a reassuring manner, taking into account religious and cultural connotations. Make a box of tissues, sip of water or a cup of tea available, to be used if needed.

Plan the next steps and follow up

Treat current symptoms and explain the plan for additional treatment. Arrange appropriate referrals. Discuss and agree on a follow-up plan with the patient and the family but be sure to address unrealistic expectations carefully.

Chapter 7. AT THE TIME OF DISCHARGE FROM THE WARD

KEY POINTS

- A discharge meeting should take place with the patient and a family member who is going to take care of him/ her.
- One should have ample time for the meeting, discussion of the discharge plan and any procedures required for long term management.
- A contact person or place for advice should be given to the family for any further assistance.

For minor, mild, and even for severe illnesses from which complete recovery is expected, there is no major problem with providing details at the time the patient is discharged from hospital. However, when a decision is made on the requirement for long-term follow up for a patient, it is suggested that the following guidelines be followed.

- All such patients need a detailed **discharge plan** to be discussed when they plan to go home
- The date for the subsequent first visit ought to be set near the date of discharge depending on the medical condition
- Wherever possible, the members to be present at this meeting are
 - Patient
 - Family member/ care giver/ parent
 - Nursing officer
 - Junior medical officer
 - Consultant in charge (ideally) or a named representative
 - Doctors/ allied health professionals from specialised field i.e. Neurologist, physiotherapist, when required
 - In an ideal setting, the following professionals
 - MOH/ MO Non-communicable disease/ GP (Primary contact level)
 - Social Worker
 - Probation Officer (in case of abuse/ violence)
 - The Midwife from the baby's area (in the case of a baby)
- The **documents** to be handed over on discharge include :-
 - The Diagnosis Card/Discharge Summary
 - Any investigation results pertaining to the diagnosis and the investigations carried out to support or look for complications of the diagnosis. This depends on the prevailing policies of the unit and on items that could be released)
 - Prescriptions for medications for an adequate duration
 - Details about any long term medications and instructions regarding administration
 - Referral letters to the local Physician, Paediatrician, General Practitioner(GP), Medical Officer of Health (MOH), specialized services such as rehabilitation
 - Any booklets or leaflets containing information about the condition

- Details regarding their follow up should be clearly written in a document. *IN AN IDEAL SCENARIO, THE MIDDLE GRADE OR JUNIOR DOCTOR ALLOCATED FOR THIS PATIENT SHOULD GO OVER THE DIAGNOSIS CARD IN DETAIL, WITH THE PATIENT AND THE FAMILY, AND CLEAR ANY DOUBTS AND QUERIES.*
- Ensure that the **necessary training** for the patient and family has already been provided to deal with some of the probable consequences related to the condition for which the patient has been originally brought in. This includes training the family on practical requirements for the clinical condition.
 - Some examples are administration of subcutaneous insulin, management of a seizure / fit at home, intermittent clean catheterisation, using the inhaler for wheezing, tube feeding etc.
- Hand over all **referral letters/ request letters** for assistance to the family or caregiver so that they could present them to the relevant authorities.
- When a patient needs management in a specialized unit it is best that on discharge or transfer, arrangements are made for the patient to be followed up in a general medical/ surgical/ paediatric unit as well. In addition, or whenever relevant, the services of a Multi-disciplinary Team could be obtained. Examples are an adult who undergoes renal transplantation or a newborn that requires surgery for a meningocele.
- General principles to be followed during a discharge meeting and a guide to the procedure are as follows :-
 - Get the permission of the patient for the family to be present at the meeting, in case of a child both parents should be there whenever possible
 - Use clear and simple non-medical language, use diagrams, books and videos whenever possible
 - Give positive information to start off with. Some examples are :-
 - “Although you have been infected with HIV, the good thing is your white cell counts are within the normal range”. “You have a Down syndrome baby. They are often very loving and lovable”.
 - Be realistic about the condition but do not overload with information. Give adequate time for the patient/family to digest the information and ask more questions.
 - ***Remember though this is your discharge meeting they may behave as if they have never heard of the things that you are talking now. This is because they are in denial and shock. Please do not get angry and impatient. They may even ask the same question more than once !!***
 - Relax, and if you do not know the answers to some questions, feel free to tell them so and also, tell them that you will collect the necessary information for them in the near future. Please make a note and do remember to try and find the answers for the next meeting.
 - Set a date for another meeting at the next clinic date.
 - Give a point of contact for emergencies
 - Give a contact number of a patient or parent group whenever possible, provided prior consent has been obtained from those concerned.

Chapter 8. SPECIFIC CONDITIONS

KEY POINTS

- There are some general principles that have to be followed in conveying information on certain important diseases.
- These include adequate preparation and the actual process of providing sensitive information.
- Specific situation would need special provisions.

General Notes :-

Prepare for the consultation

This information must be transmitted in person.

Even if it becomes necessary to contact the patient or a relative over the telephone, as may happen with laboratory reports coming in later, it is best to tell them to come for a discussion.. Do not avoid seeing the patient or leave them anxiously waiting for news. Sometimes anticipation can be worse than even the worst reality. *Treat others as you would wish to be treated yourself should be the motto.*

Ensure you have dedicated time. To you this may be just another day at the office but to the patient and the family it is a pivotal day of their lives.

Make yourself as fully conversant with the facts as possible.

You may invite a registrar or medical student to be present, but ONLY if they can be unobtrusive and be in the background

During the consultation

Use language that the patient will understand and give plenty of opportunity to interrupt if they want something elucidated.

Find the patient's starting point. What do they know already? What have they been led to expect?

Break the consultation into stages like diagnosis, implications, treatment, and prognosis and if appropriate, be reassuring about terminal care. It is the terminal stages that people fear most. It is not essential to cover all aspects immediately if you feel it will be too much to take in at once.

Patients will vary in the amount of honesty they want and may appreciate some ambiguity if the prognosis is very poor; an individual assessment will need to be made. Honesty includes being honest about what you do not know. If you are unaware you may state that "I am unable to give you exact figures but the doctors at the specialist hospital would let you know about the exact probabilities according to treatment outcomes in the Sri Lankan Setting."

Observe the patient and see how he or she is coping. Is now the time to discuss treatment or will that be better in a few days time? How much does the patient really want to know? Read the subtle signs. If in doubt, ask outright. Do not expect to deal with everything in one session.

Agree on a plan for further follow up. If there has been a lot of information to impart, this will need repetition or clarification in the future.

Concluding the consultation

Finish with a summary, a pleasant parting phrase and try to conclude on an "upbeat note".

It may go something like this: *"You know that you are having an illness which needs long-term treatment. We have been able to help a lot of people who had these types of problems. Sometimes, going through the process will be bit difficult. You have a fight to take on. One of the most important features is your attitude. Please remember that if you have any problems or want to discuss anything we are here for you"*.

You may also make a follow up appointment. Try to leave on a positive note.

Imparting sensitive and significant news is an emotional experience for the doctor as well as for the patient, so take a moment to recognize this and calm down before moving on to the next consultation.

FOLLOWING ARE SOME EXAMPLES OF SPECIFIC CONDITIONS.

(Please note that due to constraints imposed by limitations on space, only a few are highlighted.)

Malignancy

You must familiarise yourself with the exact type of tumour and stage, as well as more general issues about the disease.

A warning shot to prepare them may be helpful. "I am afraid that it is a rather serious condition". Give this a moment to sink in.

With the initial few words, check whether they are in a mood to accept further discussion. If the patient is reluctant to discuss further or seems to be terribly distraught, there is no harm in postponing the exercise.

Explain to the patient and the relatives, in non-technical words, what has actually happened and what stage now the patient is in. Please keep in mind that they may not understand the tumour staging..

Most importantly, discuss the options available for treatment, survival rates, expenditure balanced against the outcome.

If it is not an urgent decision let them discuss among themselves and let you know their decision on the following day. Then the plan of management could be finalized. If you are not going to provide the treatment do not be too optimistic or pessimistic about the prognosis and inform them that the patient could get more details from the cancer hospital or at the centre to which you are planning to transfer the patient.

If the treatment modality is conservative, a smile, a gentle tap or a couple of friendly words during the daily ward rounds will help the patient to be happy, even till the next day when he is likely to see you once again.

Birth of a child with congenital abnormalities

The birth of a child with congenital anomalies may be an expected or unexpected event. Now it is possible to diagnose most of the anatomical defects in the fetus before birth by sophisticated ultrasound scans performed by experts. However these facilities are limited to urban centres and unexpected deliveries of newborn babies with such anomalies still take place at many hospitals in Sri Lanka.

In either situation it is vital to provide information in the most appropriate manner to these families to minimize the psychological trauma and to optimize the future care of the child.

When a fetus is diagnosed to have multiple congenital anomalies while in the womb, the obstetric team together with the paediatrician and any other experts whenever necessary, need to discuss this finding with the parents. In those defects that are invariably lethal it is important to be honest about the outcomes and discuss about the kind of care that needs to be given if the fetus is born alive.

The decisions need to be documented and handed over to the team attending the delivery.

However, the more difficult situation is when a child with multiple congenital deformities is born without any life threatening complications. In such a situation, one needs to be guided by ethical principles and what the parents wish as well.

Most unfortunately, mothers anecdotally report that their first experience on the condition of the child was in the labour room or the operating theatre when the medical staff made multiple negative comments about her child without being aware of the presence of the mother and not realizing the gravity of the news they were breaking.

It is important to be aware of this fact and be sensitive to the possible immediate impact of such information on the family. It is also essential to acknowledge the fact that this family has undergone the process of pregnancy and birth similar to any other family and will hold many dreams and wishes for their new born infant.

Some anomalies are clearly noticeable even to a lay person eg: cleft lip, a limb anomaly etc., whilst some are less obvious eg: Down Syndrome, microcephaly. Therefore, the time of breaking the news may vary from just after birth to a few days after birth. It is best to break the news at the earliest possible time when you feel that the family is ready for this.

When speaking to the family it is essential to follow the guidelines outlined in other sections of this booklet.

Given below are some of the finer points rather specific to these situations.

1. **Ensure mother-child bonding.** This is extremely important.
2. Unless the clinical condition clearly necessitates separation of the baby and the mother it is never advisable to admit the baby to a special care baby unit. Children with conditions such as Down Syndrome, facial dysmorphism, limb deformities or even a meningomyelocele, do not routinely need admission to a SCBU. **Always talk about the positive aspects first.**

This of course needs to be culturally appropriate e.g: in Western countries one generally uses the phrase “Congratulations on the birth of your new baby”. This would be their opening sentence irrespective of the fact whether you have a baby with deformities or not since that factor is secondary to the good news of the birth.

Such a practice may be difficult in a culture where doctors generally do not congratulate parents on the birth of their newborn. In such a scenario, one would have to use his or her instincts and phrase the opening sentences to be pleasant and conversational in a way that initiates a good rapport with the parents. Different situations would invariably require different approaches. The first few sentences often need to be spoken in such a way as to be somewhat positive and in a way which is unlikely to have negative implications.

3. Carefully discuss the possible **complications** and the setbacks the child may have due to this condition
4. Indicate at this early stage that they are not alone during this journey, you as the clinician and your team are going to share some of the burden with them.
5. **Explain** in detail, **demonstrate** if necessary and **train** the parents to carry out any procedures required to handle complications due to the abnormality. e.g: feeding a child with a cleft palate
6. Inform them of all the locally available services to improve or treat the condition.
7. Impress upon them the importance of **early intervention**.
8. If committed **parent-support groups** are available it is always advisable to get them involved with the family at the earliest possible opportunity.

Communication in conditions associated with social stigma

Disease related stigma could very well qualify as the most troublesome and perilous form of social stigma. In some cases it forms an insurmountable barrier which prevents patients/or families seeking even life saving care. It is sometimes powerful enough to incite violence and malicious enough to drive a wedge between families, among communities and even among countries.

Disease related stigma often persists without any rationale even in spite of public health education. This fact must be borne in mind when communicating with patients and families. While applying general principles of rational medical communication, the following special points may be useful to consider in situations which may be associated with stigma.

Exclusion or rejection from school, work, social groups and activities, blame and devaluation, diminished self esteem and possible social impact on family are some of the contributory factors to this phenomenon of reluctance to disclose and discuss about the illness.

It is therefore essential to build up a good rapport between the patient and the clinician in order to build up confidence. This will minimize the reluctance to disclose and discuss the problem.

The kind of communication based interventions for conditions that may be associated with stigma varies from one health problem to another. In

communicating with patients with health issues resulting in social stigmas the communicator must first analyze the related issues. The following domains may serve as useful guidelines to this analysis.

1. Health issue/problem
2. Stigmatizers as perceived by the patient/family/community
3. Emotional impact of the “stigma” on the patient/family
4. Prevalent social policies

Once the factors associated with each domain have been identified, the communicator must, together with the patient/family, prioritize the issue/s which would have the most benefit to the identified health problem in reducing the stigma which the patient/family/community may perceive. This process may require a series of consultations and discussions.

The following table gives a guide to the factors which should be taken into account in communication in conditions which are likely to be associated with stigma.

Focus	Approach
Health problem e.g: HIV/AIDS Leprosy	Public health to control the disease Early recognition and treatment for cure or disability prevention
Stigmatizers e.g: Epilepsy Various infectious diseases Asthma	Explore Ideas, Expectations and Concerns Social marketing to enhance compassion and reduce blame Correct misapprehensions of risk
Emotional impact eg: Mental health problems	Counselling Peer support groups and therapeutic communities

*** These examples are illustrative but are not a complete and comprehensive listing.

Stigma-mitigating strategies are not limited to a single focus or approach.

Communication in patients with Non-Communicable Diseases (with particular reference to diabetes mellitus)

Diabetes is a serious and lifelong condition in which patients play a major role in the management. The disease has several implications that have repercussions on diabetic morbidity and mortality. Hence, the role of proper communication in the management of diabetes should always be an integral part of its pharmacological and non-pharmacological management.

The primary function of medical personnel in terms of communication in diabetes is to play a facilitator role to help bring about behavioural changes in patients which will help them to control their illness in a sustainable manner.

The following should be part of the communication strategy with a patient with diabetes.

1. It is essential to impress upon the patient the fact that diabetes is a lifelong disease from the point of diagnosis and that it cannot be “cured”.
2. With proper care it can be controlled to an extent which would enable patients to lead near normal lives with excellent quality of life. Such proper care includes regular treatment/follow up, appropriate diet, exercise and general life style modifications to achieve better health status.
3. Patients should be informed in the simplest possible terms
 - a. What diabetes is – symptoms and signs
 - b. What happens due to diabetes to various organs and how that impacts on the patients overall health status and well being
 - c. The importance of regular monitoring of blood sugar and blood pressure (and any other relevant haematological or biochemical parameter). This includes self monitoring.
4. The importance of active patient participation in all aspects of management must be stated and reinforced as frequently as deemed necessary.
5. Specific instruction to patients control of diabetes when they fall ill due to common medical conditions, such as respiratory tract infections, urinary tract infections, gastro intestinal infections, home accidents (cuts, falls) etc.
6. Specific instructions on foot care
7. Importance of early screening of immediate family members for diabetes.

It is crucial to get at least one member of the family or a close friend intimately involved in the active management of the condition along with the patient.

Communication with Patient’s family in Brain Death

Communication with Patients’ Family when a patient is “Brain Dead” is an important and unique situation that requires exceptional communication skills. In the present context we could classify this situation into 2 major scenarios,

- (A) Communication with the family **without** any intention of securing organ transplantation.
- (B) Communication with family in a patient who has planned to donate organs.

Since many ethical and practical aspects are involved in these scenarios, communication is best done in a stepwise approach.

1. Explain the Patients’ Situation to the Family

Explain the severity of injuries / illness in simple terms. You may have to repeat the explanation several times.

2. Keep the family updated on patients' worsening condition

Explain that despite your best efforts the patient is deteriorating. Inform the family about the efforts you have made to save the patient. (Given blood and fluids, used medication to support the Blood Pressure, etc). Allow the family to observe resuscitation efforts.

3. Inform family that patient appears brain dead.

Explain the family the term "Brain Death" using simple language without medical jargon. Explain the procedure to test for brain death.

4. Explain to family the results of brain death testing.

Explain that the patient is brain dead and can't be revived.

5. Allow the family to visit the patient.

Allow the family to spend time with the patient. Incorporate a member of the family to the medical team.

When caring for Donor Families, following are some important considerations :-

Do^s	Don't^s
<ul style="list-style-type: none">• Organize your thoughts and explanations beforehand. Take time to practice what you wish to express in layman's terms.• Use words Death/Brain Death. Don't avoid them.• Allow moments of Silence.• Be patient. Let family members grasp the situation at their pace, not yours.	<ul style="list-style-type: none">• Don't give a rushed, incomplete explanation. Spend time with the family.• Every family is unique. Adapt to the content and adjust your style of communication to suit the family.• Don't do all the talking. Let family members express their own thoughts.• Assess how the family understands the information you are giving them.• Allow time for questions/clarifications.

EPILOGUE

The primary objective of this collaborative project from the Sri Lanka Medical Association is to help and facilitate proper and acceptable communication practices between medical professionals, their patients and relatives. We believe that it is a sacrosanct duty of all medical professionals to communicate with patients and their relatives in a most human and humane way.

It is with this sense of responsibility and infinite trust that the SLMA is pleased to dedicate this book to patients from all over this resplendent isle.

Our fervent hope is that this venture in providing a synopsis of guidelines and advice on communication procedures to medical professionals would go some way towards making the burden and suffering of our patients that much lighter.