



**COMMUNICATION
IN THE INTENSIVE CARE**

A PRACTICAL GUIDE

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FOREWORD

Friends and Colleagues,

It is indeed an honour to be able to write a foreword for this first manual on communication in the intensive care unit which is the fruit of labour by a group of keen and like-minded individuals.

Malaysia is indeed a special country because it has a blend of multiple races, cultures and religions. Therefore, working in an intensive care unit in Malaysia poses a greater challenge when one needs to communicate effectively. For the families, this is a demanding and frightening time. Hence, one needs to be kind, understanding and compassionate to be able to guide them through these trying moments. We need to be able to communicate effectively with knowledge and empathy.

This book endeavours to outline both verbal and non-verbal aspects of communication. We strongly believe that effective communication with the families can actually help them accept the outcome, keep potential lawsuits at bay and create a pleasant working environment.

I take this opportunity to thank the panel of authors and reviewers for their untiring efforts. Please remember that putting what we read in this manual to practice is most important. Good communication skill is like an uncut diamond that needs time and persistent integration in our daily lives to allow it to sparkle.

Thank you.

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CHAPTER 1: INTRODUCTION

The daily affairs within the ICU demand skilled communication from all members of the ICU team. However, the nature of intensive care practice places a lot of pressure on the staff which may compromise communication with each other, the patients and their families. Good communication is often perceived as time-consuming, unnecessary and ‘too hard’ and the challenge is to rise above this. Patients and families are also suffering in their unique situations. The patient who is unable to communicate his wishes and the family who is frightened, grieving and whose needs are unmet remain a constant challenge.

Patients are often unable to participate in their own management plan, thus families are sought for discussions and decisions. While still trying to come to terms with the shock and grief of acute life-threatening illnesses, decisions may need to be made urgently and the solutions are seldom straightforward. Hence, our empathy and guidance are required to help them face this difficult time.

In advanced stages of chronic illnesses, patients and their families look to our experience and guidance to help achieve compassionate outcomes for themselves and their loved ones. Doctors from other teams may seek our opinions on the burdens and benefits of intensive therapy for this group of patients. Thus, we need to be able to communicate effectively, with knowledge and empathy.

This book is meant to be a practical communication guide for intensive care professionals. It is a culmination of literature review, clinical experience, observation from daily practice and from a series of End-of-Life Care workshops conducted over a few years. Findings of numerous research is testament to the importance of skilled communication in enhancing doctor-patient relationship, improving patient and family participation as well as facilitating decision-making. All these play a crucial role in minimising conflict while ensuring patients and families’ wishes are met.

Each chapter in this book is designed to stand alone and therefore overlaps are necessary. Some chapters in this book include case scenarios from actual events that have taken place, though identities have been changed to ensure anonymity. Each interaction has its own complex communicative issues and this book takes on a systematic approach in dealing with them. Suggested verbal and non-verbal cues are also provided, not only to illustrate certain points, but also guide actual practice. Phrases in Bahasa Malaysia have been included in the scenarios as majority of our interactions are conducted in this language.

A chapter has been dedicated to emphasize the crucial role nurses play in caring for the critically ill through effective and compassionate communication. It displays the multifaceted roles they play as caregiver, patient's advocate and liaison between families and clinicians. Communicating with the non-communicative patient as well as communication aspects at the end-of-life and during critical incidents have been emphasized in separate chapters, reflecting the varying demands required of health professionals in this field.

Considering the clinical situation from the patient or family's perspective and taking the time to reflect on each case individually, will help us improve communication. We may not be able to save everyone that comes through our ICU doors but for the patients, we can help them come to terms with their illness and lessen their distress. For the families, we can help them accept, find comfort and obtain closure.

*"You never know when a moment and a few sincere words can
have an impact on a life"*

- Zig Ziglar -

CHAPTER 2: COMMUNICATION BASICS

Communication in the health setting is important in almost all stages of medical care. Good communication skills among ICU team members, patients and families is the foundation to providing good quality care. Healthcare professionals face enormous challenges when communicating with patients who may be in physical and emotional discomfort and with families who may be in distress. In fact, communication has been identified as one of the key skills healthcare professionals should acquire to ensure high quality patient-centred end-of-life care.

Communication may be further complicated by differences in cultural and educational background. Moreover the stressful and demanding nature of caring for the critically ill and the limitations of the workplace environment can negatively impact on communication.

Communication barriers in the ICU

Barriers to communication can either arise from the patients, their families or healthcare professionals. We need to be aware of these barriers as they may prevent open and effective communication. These barriers may lead to communication breakdown which is an important contributor to conflicts. The following are some barriers with suggestions to overcome them.

COMMUNICATION BARRIERS: PATIENTS AND FAMILIES	
FEARS	
<ul style="list-style-type: none">• Being judged• Being perceived as ungrateful• Breaking down and crying• Burdening healthcare professionals	<ul style="list-style-type: none">• Causing distress within family• Being unable to voice their thoughts• Hearing bad news
Possible measures	
<ul style="list-style-type: none">• Greet patients and families• Set the tone that communicates openness and concern from the beginning• Assure them that showing emotions are normal and acceptable <i>“Most people in your situation react the same way...”</i>• Express your support <i>“I am here to help...”</i>• Invite them to talk about how they feel	

BELIEFS

- Clinicians should already be aware of complications of the illness and manage them
- Clinicians are only interested in certain types of problems
- This is not the 'right' professional person to talk to
- Healthcare professionals are too busy
- Healthcare professionals cannot be questioned

Possible measures

- Show positive regard. Show them that they are respected and valued
- Clarify misconceptions, fixed ideas or prejudices patiently
- Dedicate time to speak to the patients and families on a regular basis

COMMUNICATION CHALLENGES

- Language barrier
- Cognitive and sensory impairment
- Difficulty finding the right words
- The right questions were not asked
- Problems hinted at but not picked up

Possible measures

- Listen carefully
- Ask open questions
 - "How are things with you today?"*
 - "What are your concerns?"*
- Invite them to ask other questions:
 - "Is there something else that is worrying you?"*
 - "Is there something else that you would like to talk about?"*
- Use simple language. Avoid jargon
- Use an interpreter when necessary
- Be aware of unspoken needs

COMMUNICATION BARRIERS: HEALTHCARE PROFESSIONALS	
FEARS	
<ul style="list-style-type: none"> • Unleashing and dealing with strong emotions • Being the bearer of bad news • Facing difficult questions 	<ul style="list-style-type: none"> • Taking up too much time • Facing our own failure • Dealing with conflicts
Possible measures	
<ul style="list-style-type: none"> • Show professionalism • Dedicate adequate time 	<ul style="list-style-type: none"> • Plan what to say and anticipate questions • Do not view death as a medical failure
BELIEFS	
<ul style="list-style-type: none"> • Patients and families should deal with their own emotional problems • Discussing inevitable problems will just be a waste of time • Patients and families are unable to comprehend the medical complexities 	
Possible measures	
<ul style="list-style-type: none"> • Manage the patient and family in a holistic manner • Show empathy and acknowledge feelings • Be sensitive and flexible • Demonstrate awareness of the impact of critical illness, dying, death, and bereavement • Realise that the way we deal with them will impact their acceptance and closure 	
LACK OF CONFIDENCE OR SKILL	
<ul style="list-style-type: none"> • Starting end-of-life discussions • Exploring concerns 	<ul style="list-style-type: none"> • Handling difficult questions • Saying the 'right thing'
Possible measures	
<ul style="list-style-type: none"> • Plan what to say and anticipate difficult questions • Prepare information in a range of format e.g. pamphlets, diagrams or simple written text • Recognise their priorities and ability to communicate may vary over time • Identify good communicators among colleagues, observe and learn from them 	

WORKPLACE-RELATED	
<ul style="list-style-type: none"> • Lack of support from colleagues • Lack of privacy • Time constraints 	<ul style="list-style-type: none"> • Noise/distractions • Unsure how to seek psychological support
Possible measures	
<ul style="list-style-type: none"> • Share information appropriately with colleagues • Work as a team 	<ul style="list-style-type: none"> • Allocate adequate time and place • Speak to colleagues, superiors or counsellors

Most challenges and barriers to communication can be overcome with effective interpersonal communication skills, which contrary to popular belief, may be acquired through education, training and observing clinicians with good communication skills at work.

Interpersonal communication skills

Interpersonal communication can be defined as a two way communication between two individuals or within a small group. This involves the sharing of information and feelings with the aim of establishing trust that has direct implication towards better health outcomes.

Interpersonal communication involves both **verbal** and **non-verbal elements**. Many may not realise that non-verbal communication or body language has a greater impact on the meaning of the intended message. In order to achieve effective interpersonal communication, healthcare professionals need to improve both their verbal and non-verbal communication skills.

1. Verbal communication

Effective verbal communication can be achieved through the following:

- Organise information
- Decide on not more than five important points.
- Say what will be covered and then provide the details.

“Miss Shakira, I am going to explain to you what has happened to your father. As you know, he had a stroke which made him unconscious and because of that, he is unable to clear his phlegm. So, we had to put a tube in his windpipe to help him breathe and clear his phlegm.”

- Provide appropriate explanations
 - Tailor the information provided.
 - Take into consideration patient and family needs, educational and cultural background. Often, clinical tasks which are considered routine to a healthcare professional may be completely foreign to them. Explaining these tasks indicates respect and helps them feel more involved.

Example: Daily update of a patient with severe malaria

Family A is satisfied with broad descriptions of the patient's progress, rarely seeking further information, even after inviting them to question.

"Your wife's condition remains the same. Her kidneys continue to require support and her liver has not shown any signs of improvement."

Family B, on the other hand, often requests for detailed information of treatment and progress.

"Your wife's condition remains the same. Her conscious state is still poor due to the sedative drugs that she needs. Her kidneys continue to require continuous dialysis. Her liver functions have not improved. In fact, she is more jaundiced and has increased bleeding tendency that requires plasma transfusion."

- Use common words, not medical jargon

Say *"Your father has bacteria in his blood which has caused many of his organs to shut down,"* instead of *"Your father is in septic shock and has multi-organ failure."*
- Allow them to tell their story and to express themselves. Such insights can help us to understand their wishes and formulate a treatment plan.

"Tell me what's going through your mind..."
"How are you coping?"

- Be honest
Let them know what we are thinking. Sharing our thoughts may encourage them to participate more actively in the discussion.
“In my opinion, adding this therapy will not benefit patients at this advanced stage of their illness, like your father....”
- Verbalise active listening
Many undermine the importance of listening as part of effective communication. Listening actively and attentively communicates positive messages to the patient and family. Listening well encourages others to participate in the interaction and enhances the overall exchange of information. This can help clinicians to set the pace and tone of discussions.
 - Acknowledge feelings of others.
“I can see that you are upset.”
“You sound very upset.”
 - Check your understanding by paraphrasing.
“So you think that your father would not want this type of treatment plan.”
 - Show your effort to understand by asking for clarification.
“What are the things troubling you?”
 - Check that nothing important is missed by summarising.
“So, what’s most important for you is...”

2. Non-verbal communication

Words express only part of a message while tone and body language convey the rest. Non-verbal cues are the first signal to indicate our level of commitment and engagement, even before verbal communication begins. Even though the right words are chosen, if non-verbal cues signal otherwise, the message is lost. In contrast, simple non-verbal gestures, such as a warm smile or an interested body stance can put people at ease and enhance communication.

However, some non-verbal cues are specific to cultural customs. For example, eye contact is a sign of positive regard and respect in some cultures, while in others, it is deemed improper. Similarly, physical contact during a conversation is considered a sign of warmth, while in others it might be unacceptable. Therefore, we must constantly be mindful of our gestures as it is a silent but powerful communicator.

Non-verbal cues

- **Eye contact**
 - Helps convey respect, empathy, interest and warmth.
 - Shows we are listening actively.
 - Helps to detect emotional distress.
 - Break eye contact at times when speaking to signal non-provocative stance.
 - Avoid staring and rolling of eyes.
- **Body stance**
 - Maintain a non-threatening and open body posture. Stand straight and balanced.
 - Avoid folding arms or placing both hands on the waist.
 - Avoid being overtly casual, for example leaning on furniture.
 - Avoid shaking legs.
 - Maintain eye level position. Stand up if the person is standing.
 - A forward lean, whether standing or sitting, implies the desire to genuinely want to hear what others have to say.
 - Be aware of personal space. This is especially important when dealing with an angry family member or a confrontational colleague.
- **Facial expression**
 - Expression should be aligned with the verbal message.
 - Maintain a professional facial expression - do not allow emotions (e.g. anger, irritation, annoyance) to manifest.
 - Nod to show attentiveness and agreement.
 - Avoid pursing lips.
 - Avoid raising eyebrows.
- **Tone of voice**
 - Maintain a neutral tone. Do not reveal negative emotions. Avoid sarcasm.
 - Control the volume.
 - Speak firmly during conflict.
 - Use pauses strategically when explaining complex or difficult issues.
 - Remain silent when faced with an angry outburst.

- **Hand gestures**
 - Avoid finger pointing.
 - Avoid distracting hand gestures. For example fidgeting with objects, tapping fingers.
 - Avoid aggressive gestures especially in conflict.

- **Active listening**

Demonstrate active listening via non-verbal cues. Being sensitive to the non-verbal cues is important as it reflects emotions and understanding of family and patient. This helps to establish rapport.

 - Give your undivided attention by maintaining eye contact.
 - Lean forward to show attentiveness.
 - Show that we are actually listening by providing minimal responses.
 - “Yes, yes, hmmm...” and [nods].
 - “Yes, go on...” and [nods].

- **During an angry encounter**
 - Stay calm and be aware of one’s body language.
 - Avoid a threatening or condescending posture.
 - Be aware of personal space.
 - Remain silent when faced with an angry outburst. Do not interrupt.
 - Maintain non-threatening eye contact. When speaking, break eye contact from time to time to signal a conciliatory stance.
 - Control the volume of voice and maintain a neutral tone.
 - Do not raise your eyebrow.
 - Do not purse your lips.
 - Use calm gestures. Avoid finger pointing.
 - Avoid touching in an attempt to pacify.

CHAPTER 3: COMMUNICATING WITH THE PATIENT

Many critically ill patients experience difficulty to communicate. This difficulty may be attributed to being intubated, cognitive or sensory deficits from sedatives and underlying illness, or language barrier. Difficulty in communication can be a terrifying experience for these patients and may be associated with psycho-behavioural symptoms e.g. panic, frustration, sense of isolation and helplessness.

For the non-communicative patient, head nods, mouthing of words, hand gestures and facial expressions are common methods of communication. Communicating in this way may not come naturally for both healthcare professionals and the patient. It is imperative that we are constantly alert, remain patient and persistent to the patient's effort to communicate.

Assessment of communication

Assess the following functions and abilities to better understand the patient's difficulties, thus facilitating communication.

- Presence of sensory deficit caused by impaired vision or hearing. Ascertain if the patient uses glasses or hearing aids.
- Preferred language for verbal or written communication.
- Cognitive function by testing if the patient can follow commands e.g. to raising of arm, blinking of eyes.
- Emotional state e.g. withdrawn, upset, cheerful.
- Presence of receptive or expressive aphasia.
- Presence of dyspnoea as it may reduce verbal communication.
- Upper limb motor function by asking the patient to point or write.
- Oral motor function by asking the patient to count from one to ten.

Determine the best method of communication with the patient, whether verbal, written, gestures, communication aids or a combination at the end of the assessment.

Strategies to facilitate communication

1. **Ascertain if patient wears glasses or hearing aids and keep them within reach**

2. Greet and smile

- This ensures that patient is aware that we will begin interaction.
- Helps to break down barriers and sets patient at ease.
- Keep distractions and background sounds to a minimum.

3. Initiate conversation

- Initiate interaction regularly as the patients are often unable to do so.

Nurse : *Miss Lim, are you in pain?*

Patient : [grimaces]

Nurse : *Miss Lim, you look like you're in pain...* [pauses]

Patient : [nods]

Nurse : *OK, I will give you an injection for your pain* [makes gesture for "injection"]

Patient : [nods again]

Nurse : *Mr Rama, how are you?*

Patient : [looks to pillow]

Nurse : *You want me to prop the pillow?*

Patient : [nods]

4. Lean forward with an open body posture

- An open posture suggests willingness to interact and being approachable.
- Stand close within patient's line of vision when speaking. Seeing the person's face or lips enhance what is being said.

5. Maintain eye contact

- Eye contact conveys that one is paying attention to the individual.

6. Talk at a slow, even pace

- Speak slowly to ensure patient's attention.
- Speak clearly. Do not mumble.

7. Use short sentences when giving explanation or instruction

- Say the word or phrase slowly and clearly.
- Repeat key words to avoid confusion.
- Instruct on what the patient is capable of doing physically e.g. "*point to where the pain is*", "*open your mouth*", "*nod your head*".

8. Use gestures

- Use gestures together with verbal communication.
- For example before suctioning secretion inform patient verbally while gesturing intended action.
- Be sensitive. Patients often can read our body language, sincerity and mood.

9. Read non-verbal cues

- Observe the patient attentively for clues in the tone of voice and facial expression.

10. Repeat and mirror after the patient

- Reiterate what the patient has said to verify understanding.

Patient: *Leg...leg...hhu...hurts...*

Nurse : *Leg hurts? Your leg hurts?*

Patient: [nods and glances at right leg]

Nurse : *Your right leg?* [points to right leg]

Patient: [nods]

Nurse : *Is it painful?*

Patient: [nods]

11. Ask yes or no questions

- This is the easiest way for patients to respond.
- Try to phrase questions that the response is such.
- Rehearse with patient how to signal yes or no before asking questions. These signals may include nod your head for yes or shake your head for no. Others include thumbs up for yes or thumbs down for no.
- Ask if patient prefers to point to yes or no using a communication board.

12. Ask one question at a time

- Allows patient to stay focused on one thought as too many options may cause confusion.

Patient: [points to mouth]

Nurse : *You want something to drink?*

Patient: [shakes head]

Nurse : *Suction?*

Patient: [nods]

Nurse : *Suction, okay. I'll do it now.*

13. Allow patient ample time to respond

- Non-verbal patients take longer as they have to think of how to respond and deliver the message without speaking.
- Patients on sedatives require longer time to initiate movement including mouthing words or gesturing.

14. Interact consistently

- Keep conversation natural and meaningful. Example talk about families and hobbies. This helps to establish good rapport.
- Continue to have a one-way conversation even with a totally non-communicative patient who does not respond. For example, explaining a procedure in a comatose patient.
- Unresponsive patients may still be aware and understand.

15. Seek the assistance of an interpreter if patient does not speak the same language.

16. Use communication aids

- Examples: writing pad and pencil, tablet, alphabet board, word and phrase cards.
- Use a marker pen to improve grip.
- Write down key words.
- Write in lower case.
- Do not underline words.

17. Avoid the following:

- Speaking in a loud voice.
- Interrupting as the patient may be planning what to say next.
- Pretending to have understood. If having difficulty, be honest and say:

“I’m sorry, I don’t understand. Let’s try again.”

- Completing patient’s sentence as it may frustrate him. Ask for permission before helping if he appears to be having difficulty.
- ‘Talking down’ to patient. He may feel patronised or undervalued.
- Restraining patients as it hinders hand gesturing and use of alternative communication aids such as letter boards or writing. Physical restraints may indirectly impede communication by contributing to feelings of stress, anxiety and depression.

CHAPTER 4: MEETING THE FAMILY

Doctors often discuss a patient's status, treatment plan, and medical decisions with family members. This may occur at the patient's bedside or in a private room. A family conference is a planned formal encounter with relevant family members. This is a well-established communicative platform for:

- Updating patient's progress.
- Delivering bad news.
- Discussing a decision point e.g. when changing treatment direction from a curative to a palliative intent.
- Resolving conflict e.g. when family members disagree with the course of treatment.

A family is an independent organisation with its own unique way of communicating. Some families talk things out calmly, some yell, and others try their best to avoid conflict. Different individuals may bring complicated relationships and interactions to the meeting. Family conferences may be challenging because individual family members may have:

- Their own interests and agenda.
- Their own personal emotional needs.
- Different preferences for information details or decision-making and may disagree with the course of action.

Communication challenges and tools when meeting with families

Challenges and Tools	Suggested Responses
Family Dynamics <ul style="list-style-type: none">• Identify patient's role in the family unit and how it has changed• Pay attention to family roles• Ask how the family usually makes decisions	<i>"Who should we talk to if we need consent for your mother?"</i> <i>"Perhaps you can share with me how you would like to discuss and decide on treatment plan."</i>

<p>Differing Opinions among Family Members</p> <ul style="list-style-type: none"> • Avoid taking sides and remain neutral • Lay down rules and boundaries for the discussion • Be firm but polite • Identify and state the point of disagreement • Focus on the patient • Reframe the disagreement neutrally 	<p><i>"I see there are differing opinions on a number of issues."</i></p> <p><i>" I wonder if you could put these aside for now, so that we can try to focus on what is going on with your mother."</i></p> <p><i>"I'm happy that we can sit down and talk about what is going on with your father."</i></p> <p><i>"I want to try and make sure that everyone present has a chance to say something."</i></p> <p><i>"I appreciate if only one person talk at a time."</i></p> <p><i>"I see you both disagree about"</i></p> <p><i>"I wonder what your dad would say if he was here?"</i></p> <p><i>"So you opt for a nursing home because you think he would get the best care there. And your brother wants him to go to his house because he thinks he will be happier. Lets think of a way to make him happy while receiving the best care."</i></p>
<p>Strong Emotions</p> <ul style="list-style-type: none"> • Acknowledge the emotions in the room • Silence may be appropriate 	<p><i>"I can see that this is very upsetting to you. Most people in your situation would be upset."</i></p>

<p>Varied Expectations for Information</p> <ul style="list-style-type: none"> • Allow family the chance to state how much information they want • Identify family members who require more information 	<p><i>“Some people want to know what happens after the ventilator is turned off while some others prefer not to know. Would it be helpful for you to know?”</i></p> <p><i>“From my explanation, does anyone need more information on....”</i></p>
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Conducting a family conference

1. Prepare for the conference

- Prepare a room to ensure privacy.
- Invite other clinicians involved in the patient’s care whenever appropriate. Ensure medical consensus has been reached.
- Invite relevant family members.
- Involve the nurse in-charge of the patient.
- Include a social worker, whenever possible, to help deal with complex family dynamics.

2. Introduce everyone present and state the purpose of the meeting

- Ask clinicians to introduce themselves and to explain their roles in caring for the patient.
- Invite family members to introduce themselves and identify the primary caregiver or surrogate decision maker, if any.
- Set the tone to diffuse any possible anxiety.

“This is a meeting we hold routinely with many other families...”
- State the purpose of the meeting.

“Shall we talk about your father’s progress so you are clear about what is being done.”

“We want to try and understand his values and wishes so that an appropriate care plan can be drawn out.”

3. Assess what the family knows and expects

- Request the family to describe their current understanding of the situation.

- Assess the family's understanding and expectations.
Family A saying, *"We don't think he will make it"* is likely to lead to a different conversation than Family B saying, *"The doctors say he's not improving, but we are praying for a miracle."* Both families realise the gravity of the situation but expectations differ. Hence, conversation about palliative care with Family A will be easier.
- Identify and correct misconceptions.

4. Describe the clinical situation

- Give a brief overview. Avoid detailed pathophysiology.
- Convey what needs to be said in simple language. Avoid medical jargons.
- Focus on two or three important issues. Avoid too much information.

5. Ask for questions and concerns

- Check for comprehension and encourage questions. Turn to other family members if one seems to dominate.
"Does anyone else have questions? Do you, Mr Lai, have any concerns?"
- Acknowledge family's emotions and concerns to signal respect.
"I can see this has not been easy and everyone is upset."
- Provide support by offering help.
"What can we do to help you get through this difficult time?"

6. Provide a management plan

- Propose appropriate goals for the patient's care based on his values. Weigh the risks and benefits of treatment.
- Be prepared to negotiate with the family.

7. Conclude the meeting

- Summarise the meeting.
- Set a date for further conference, if required.
- Ensure the family knows how to reach the healthcare team for questions.
- Document the discussion.

CHAPTER 5: NURSES' ROLE IN COMMUNICATION

Effective communication is a fundamental skill for nurses as they are constantly interacting with the patient. It can be challenging and at times complex as most critically ill patients are unable to speak and express their needs and concerns. It is essential that nurses are able to identify their needs and source of distress or anxiety and allay them. This can be achieved through effective and persistent communication. Being at the patient's bedside most of the time, qualifies them to be the patient's advocate. The nurse is also more knowledgeable about family's concerns and dynamics and hence is able to solicit key information that is not readily available to clinicians.

Nurses need to interact with other healthcare professionals, share information and concerns of patients to provide safe and quality care. A thorough nursing handover should always include communicating patients and families' concerns and fears. The challenge is for the ICU nurse to be proactive about communication, especially when multiple teams are involved in the patient's care. This helps to create an intensive care environment that is healing, humane and less stressful.

The intensive care nurses play a key role in the following settings:

1. Daily interactions with patients

Quality nursing communication should encompass empathy, attentiveness and touch. Non-verbal cues should correspond with the verbal message in every interaction.

- Introduce ourselves and orientate patient at the beginning of shift.

Nurse : *Good morning Mr Lim.* [pause] [looks at his face and touches shoulder]

Patient : [looks at nurse]

Nurse : *I am Staff Nurse Aishah. Remember me? I took care of you yesterday.* [smiles]

Patient : [smiles]

Nurse : *Do you know what day is it today?* [pause] *Today is Sunday, 3rd of February. It is eight in the morning now. You were admitted to ICU two days ago.*

- Talk through procedures with the patient.
 - Alert the patient and gain his attention before providing care.
 - Call his name aloud and pause for him to acknowledge by demonstrating head nod, facial expression or eye contact.
 - Look at the patient's face while touching his hands or shoulders gently.
 - Stay focused on the interaction. Avoid distracting or irrelevant conversations.

Nurse : *Mr Wong* [pause] *I'm going to change your dressing.*
[soothing tone]

Patient : [no response]

Nurse : *You will need to be on your side for a few minutes.* [pause]
I am going to turn you now. [turns patient]

Patient : [tenses body]

Nurse : *Are you OK?* [pause] [checks facial expression] *I am going to remove the dressing now.*

Patient : [tenses body further and grimaces]

Nurse : *I will stop now and give you more medicine.*

- Praise patient's accomplishments. Provide encouragement and assurance, when appropriate.

Nurse : *Mr Lim, you are doing well today.* [thumbs up]

Patient : [smiles and thumbs up]

- Acknowledge patient's frustrations.

Patient : [looks upset]

Nurse : *Pak Cik, it's not been a good day today.* [sympathetic tone]
We have given you medicine for your diarrhoea and hopefully it will work soon. [gentle pat on arm]

- With unresponsive patients, introduction, orientation and talking through procedures must continue.

2. Daily interaction with families

- Introduce ourselves.
- Ask the family to introduce themselves.

- Orientate the family to the ICU environment.
 - Brief them on visitation rules, hand hygiene.
 - Briefly tell them about the equipment and monitors.
- Encourage family to interact with patient by communicating verbally and through touch even when the patient is unresponsive.
- Explain progress by describing organ function.
 - *“Encik Ahmad is still requiring high doses of drugs to keep the heart pumping. However his lungs are better today.”*
- Provide reassurances for common concerns.
 - Pain relief
 - *“Mr Lim is being treated for pain.”*
 - Poor conscious states due to sedatives
 - *“Mr Krishnan is not responding to you because we have given him some medication to sleep so that he is comfortable on the ventilator.”*
 - Feeding
 - *“Encik Din has a tube in the stomach through which we are feeding him.”*
- Clarify the roles of different healthcare professionals.
- Liaise between family and clinicians. Convey family’s concerns to clinicians e.g. referral to social or welfare services.

3. Assessment of pain

Impairment in communication may lead to inaccurate assessment and inadequate management of pain. In addition to seeking yes or no responses, it is important that a nurse looks for non-verbal signs of pain. The use of communication aids e.g. pain assessment ruler can be helpful. Signs of pain and distress include:

- Facial expressions: grimacing, squinting of eyes, tense facies, tearing.
- Body movements: restlessness, irritability, agitation, shaking of head, writhing, clenching of fist, closing eyes.
- Physiological cues: hypertension, tachycardia, diaphoresis, tachypnoea.

- Ventilator dyssynchrony, coughing, biting of endotracheal tube.
- Reactions to physical examination, movement and procedures: rigidity, immobility, closing eyes, resistance, combativeness, striking the staff.

4. Management of delirium

Quality communication is essential for patients at risk of developing delirium. The following communicative strategies can help in preventing delirium or managing delirious patients.

- Introduce others who come to visit.
“Mr Subra, your mother has come to visit you.”
- Orientate by giving repeated reminders of the day, time and location.
- Explain to the patient what is to be done and to be expected before performing a procedure.
- Avoid the use of restraints.
- Avoid using medical jargon in patient’s presence as it may cause paranoia.
- Continue to have one-way conversation with unresponsive patients and encourage family members to do so.
- Ensure that visual and hearing aids of patients are available.
- Explain to families why patient may be delirious as it can be a frightening experience for them.
- Involve the family to encourage feelings of security and orientation.
- Engage an interpreter if necessary.

5. Delivering bad news

Nurses usually have in-depth knowledge of patient’s and family’s concerns, fears and expectations. This should be conveyed to the clinician prior to the family meeting. While it is usually the clinician who delivers bad news, nurses need to be present during the meeting. This is important for various reasons as they can:

- Reinforce or clarify medical information and plan with the family after the meeting.
- Offer emotional support during and after delivery of bad news.
- Alert the clinician to possible family’s misconception and provide feedback on their response.
- Communicate pertinent issues raised in family meeting during handover.

6. End-of-life care

The dying process and death of the patient will forever be in the memories of the family. The nurse must be committed to provide support and care during this terminal phase. Besides managing the physical symptoms and maintaining the dignity of the dying patient, the nurse needs to address the family's fears and concerns. The nurse ought to be sensitive to the family's loss and grief. Spiritual and cultural needs should be attended to. The role of the nurse during this time would include:

- Reassuring families that distressing symptoms will be attended to.
- Reassuring care e.g. regular suctioning and positioning will not be abandoned.
- Ensuring dignity e.g. cleanliness and hygiene is maintained.
- Allowing access and privacy while minimising distractions e.g. silence alarms, arrange chairs around bed, put down bedrails, draw curtains.
- Facilitating families in fulfilling their religious obligations and honouring the patient's wishes.
- Informing clinicians to pronounce death promptly.
- Allowing time and space for mourning.
- Answering families' queries. Be familiar with administrative affairs.
- Allowing families to perform the last office on request.

CHAPTER 6: STRATEGIES TO FACILITATE DECISION - MAKING

Medical decision-making is a complex process because it involves understanding medical facts and weighing available treatment options and their possible outcomes. However, in reality, decisions about treatment are not solely clinical. They involve combining clinical information with the values and beliefs of multiple participants. This complex decision-making is compounded by time constraints and the surrogate nature of some decisions.

A typical stay of a critically ill patient in the ICU involves a culmination of events that require major decisions to be made such as withholding or withdrawing treatment, or consent for an intervention. Decision-making discussions that are managed well with the patient, family members and healthcare professionals will result in minimal conflict. This is mainly attributed to the communicative ability and sincere efforts of healthcare professionals as well as the insights of the families. Several factors have been shown to impede clinicians and families' decision-making. It is thus important to be aware of these barriers so that we may take the necessary steps to overcome them.

Barriers to decision-making among clinicians

1. Perceiving death as failure of medicine

Impending death of a patient is predominantly viewed with a sense of failure. Clinicians are accustomed to exhausting all therapeutic options, despite falling survival rates. For clinicians, explicitly acknowledging that a patient will not survive despite intense efforts, and having open discussions about end-of-life decisions can cause a great deal of discomfort. Some may even feel that they are taking away whatever hope patients or their families may have. Others may feel they have failed to be 'good' doctors. All these issues will result in too little or skewed discussions which will have an impact on decision-making and the family's long term acceptance of the experience.

2. Fear and lack of confidence

Decision-making in ICU setting highlights the importance of competent and confident clinical guidance by the clinicians to the families. At times, clinicians are unwilling to make strong treatment recommendation and shift the burden of decision-making onto the family. This can lead to deferred decisions, unwarranted escalation of life-sustaining treatments, perpetuating unrealistic expectations and conflicts with families. Such reluctance is often driven by one or more of the following:

- Fear of legal action.
- Fear of being viewed as paternalistic.
- Fear of confrontation.
- Fear of taking on sole clinical responsibility.
- Inability to deal with strong emotions.
- ‘Attachment’ with patients.
- Concerns of prognostic uncertainty.
- Difficulty in achieving consensus with other treating teams.

3. Lack of time spent on interacting with patient and family members

When clinicians do not spend enough time interacting with the family, a foundation of trust and understanding is not formed. As a consequence, discussion on medical decision becomes uncomfortable, if not difficult.

4. Inability to understand patient’s and family’s lay perspectives

There are cultural, religious, socio-economic factors and family dynamics that clinicians need to comprehend prior to decision-making discussions.

5. Lack of communication training

There is a lack of formal training in communication. However, effective communication skills can be acquired either by attending communication workshops, shadowing a senior or experienced consultant who has good communication skills and making continuous effort to improve oneself.

This may be achieved by asking other healthcare professionals such as nurses to provide feedback for example after delivering bad news or after conducting a family conference.

Barriers to decision-making in patients and families

1. Lack of understanding

Before families can decide, they need to understand the precipitating events that led to the ICU admission as well as the gravity of the situation. Family members of patients suffering from chronic illness have fewer problems understanding the deteriorating condition of the patient. In contrast, the nature of an acute illness often leaves family members struggling to understand the severity of the illness.

2. Lack of trust

Studies have shown that a lack of trust on a member or members of the treating team may compel family members to delay decision-making. Some may resist attempts to discuss patient's deteriorating condition and treatment plan.

3. Fear of abandoning their loved ones

Family members fear that the decision they make will be perceived as a sign they no longer care for their loved ones. They may equate this as a form of abandonment that may result in long term guilt and difficulty in finding closure.

4. Lack of close family ties

In making decisions, especially to withdraw, family members try to recall patient's life journey in order to examine patient's values and preferences. Close family ties enhances one's capacity to reflect and recall moments in which life and death issues were discussed.

5. Fear of severing family ties

Families avoid making decisions if they feel that the decision can cause rifts among themselves.

6. Feeling pressured

Family members need to grapple with information both cognitively and emotionally. Hastening decision-making can be counter-productive as families may feel rushed and coerced.

Communicative strategies to facilitate decision-making

1. Organise information to be delivered

- Present medical problems clearly. Include explicit and clear discussions of the specific problems and complications.
- Avoid discussing inappropriate treatment options. If discussed, use words or phrases to highlight the futility of the option.
For example, “very unlikely to benefit”, “impossible at this stage” and “not suitable for his current condition”.
- Avoid explicit mention of any insignificant improvement in patients who have poor prognosis.
Say “His blood pressure is still maintained with very high doses of medication,” instead of “His blood pressure is more stable today,” when he is still on very high doses of inotropes.
- Remind the family about the reality of the patient’s condition. Demonstrate sequential decline in the patient’s health. This provides proof or justification which will facilitate decision-making.
- Avoid equating death as medical failure.
Avoid saying “There is nothing else we can do,” or “There is no more treatment that we can offer.”
- Offer a summary which implies the gravity of the situation and the need for urgent decision-making.
“...therefore, if we do not remove the infected leg soon, he will die.”

2. Ensure timely communication

- Inform family members as soon as possible of any significant change in the patient’s condition so that they have enough time to understand and accept.
- Clinicians need to communicate with nurses as they may be aware of families’ readiness to make end-of-life decisions.

3. Prepare the family for the possibility of treatment failure

- This should be done with discretion so that family members do not assume that the treating team has already given up hope.
“It would be good to start thinking about the kinds of treatment your father would want should he not improve.”
“We will try our very best but we must be prepared for the worst.”

4. Encourage family members to reach consensus among themselves

- Clarify family's roles as this helps to initiate decision-making discussions. Guide them to reach a consensus.

"I can see that you have different concerns but you must try to think what would be best for your mother."

- Avoid placing the burden of decision-making on one particular individual.

Avoid saying "As you are the only child, you will need to decide whether to continue with the treatment or not..." Instead say "You are the closest to him, you know his values and beliefs best..."

5. Show support for the family's decision

- Family members need to know that they have done the best under the circumstances.

"I think all of you have made the best possible decision for your mother."

"You have taken good care of your father and I am sure you will be able to decide what is best for him."

6. Assure family members that they will have access to the patient

- This is especially important in end-of-life care.

"You can be with your daughter and help out in caring for her as you wish."

7. Accommodate family grief

"It is natural to be upset but we will have to think about how we must move forward."

8. Allocate adequate time and space

- Whenever possible, allow families to reflect so that they do not feel pressured to arrive at a decision.

CHAPTER 7: DELIVERING BAD NEWS

Bad news in the healthcare context refers to any information that creates a negative view of a person's health (Buckman, 1984). In the ICU, clinicians are usually expected to break bad news to the patient's family or surrogate. It is a challenging communication task for clinicians as some families are met for the very first time. Despite not knowing the family's expectations and perceptions, clinicians need to manage their emotional response. Bad news when conveyed well, will allow for better acceptance and closure. This will also promote satisfaction with the medical care given.

Principles on delivering bad news

1. Prepare the meeting

- Who informs
 - A senior clinician with experience should inform the family. Ideally, he have had some contact with the family and continues to be involved in the patient care.
- When to inform
 - Depending on the urgency of the situation, news needs to be conveyed as soon as possible.
 - At times, bad news may need to be delivered over the phone e.g. in an unexpected cardiac arrest.
- Whom to inform
 - Ensure the relevant family members are present for the meeting. With large families, assess the situation and limit the number of family members that need to be present if necessary.
 - Identify the spokesperson and/or caregiver .
 - Do not give bad news to only one member of the family, if possible. They may need some support after the discussion for which we may not be able to provide.
- Where to inform
 - Every effort should be made to ensure privacy. Bad news may be delivered either in a separate room or by the bedside with the curtains drawn.

- Ensure adequate seating arrangement if meeting is done in a room. Clinicians should ideally face all family members to facilitate eye contact and ensure he can be heard by everyone. In a situation where aggression is anticipated, clinicians should sit closest to the exit.
- When bad news needs to be delivered to the patient, it is usually done at the bedside. Ensure there are no ongoing procedures.
- What to prepare
 - Go through the notes and ensure all facts are known e.g. patient's name, age, surgeries performed.
 - Family's perception if known, will help clinicians to be better prepared when delivering bad news. It also helps to tailor the news based on their understanding while correcting any misconceptions.
 - Mentally rehearse the message that needs to be delivered.
 - Ensure there is sufficient time to conduct the meeting.
 - Minimise disruptions. Silence hand phones.
 - Have a third person during the discussion, who may be the nurse in-charge of the patient or another fellow clinician.
 - Anticipate difficult questions.
 - Anticipate emotional response.
 - A trained interpreter will need to be present if there is a language barrier.

2. Begin the meeting

- Introduce yourself and other healthcare professionals.
- Allow the family members to introduce themselves and state their relationship to the patient.
- Be aware of anyone in the family, who is not the surrogate but exerts significant influence on decision-making.

3. Elicit families' understanding

- Ask the family what they understand of the current medical condition.
"From your previous discussions with the doctors, what have you understood regarding your father's medical condition?"
- Gauge their understanding. Rectify any misconceptions.

- Note any denial or excessive optimism.
“My father has been in hospital many times this year for difficulty in breathing but every time he has gotten better and gone home.”
- Note differences in opinion among family members.

4. Disclose information

- Give prior warning shot to prepare the family.
“Unfortunately I have some bad news to tell you.”
“Unfortunately things have not gone as well as we would like it to be...”
- Avoid medical jargon. Use layman language.
 Avoid saying, *“Your father has septic shock with multiorgan failure.”*
 Instead say, *“Your father has an overwhelming infection that has affected many organs in his body.”*
 Avoid saying, *“Your father has decompensated cardiac failure.”*
 Instead say, *“Your father’s heart is failing.”*
- Avoid euphemism.
 Avoid saying, *“He will not be himself again.”* Instead say, *“He will remain unconscious because he has severe brain damage.”*
- Be direct and truthful yet not overtly blunt.
 Avoid saying, *“There is no point in keeping that leg.”* Instead say, *“We need to remove that leg.”*
- Provide information in chunks.
- Pause to check understanding and follow up with a question.
“Was I clear with my explanation?”
“Do you need me to clarify something?”
- Continue to provide more information once they have assimilated the previous information.
- Correct any misconceptions.
- Remain silent for some time after providing the information.

5. Deal with emotions and decisions

- Provide time and space to react either in anger, shock or grief. These expressions allow families to work through their emotions.

- Listen quietly and attentively.
“I can see that you are finding it difficult to accept the news. Is there anything I can do....”
- Use appropriate non-verbal cues. For example, offering tissue paper to someone who is crying or giving a gentle touch on the shoulder.

6. Close the meeting

- Check the family’s understanding.
“Do you have any other questions to ask me?”
- Summarise the key information of the discussion.
- Inform the family of the next step in the management and care.
- Provide information on how to contact healthcare professionals.
- Arrange for the next meeting, if necessary.

7. Document the discussion

A documentation of the meeting is required to ensure that other members of the medical team are aware of the details of the meeting. Document the following:

- Names of healthcare professionals and family members present.
- Exact information conveyed to the family.
- The family’s understanding and acceptance of the information.
- Feelings of unhappiness or anger, and any disagreements.
- Further care plan of the patient.

Example of documentation

I have spoken to the Mr Chong’s wife and son, Alex, in the presence of SN Roshidah regarding his progress in ICU. Mr Chong sustained injury to his spine resulting in him being quadriplegic permanently. He is currently dependent on mechanical ventilation and there is a high likelihood that we will not be able to wean him off the ventilator. I addressed the issue of prolonged ICU stay and the following complications were mentioned i.e. repeated infections, pressure ulcers, deep vein thrombosis, depression and death. Mrs Chong was mostly silent during the discussion while Alex seemed dissatisfied with the explanation. He requested for a meeting with the surgeons. I have noted his request and will arrange for a meeting.

Case Study 1: Sudden Unexpected Death

Encik Ahmad, a 60-year-old man with diabetes mellitus and hypertension underwent an uncomplicated abdominal aortic aneurysm repair two days ago. His post-operative recovery in the ICU was smooth and he was due to be discharged to the ward. His wife, Puan Halimah and son, Adam had just visited and was relieved to find him doing well. However, Adam still has some resentment towards the surgical ward staff for administering the wrong medication to his father prior to surgery.

While awaiting transfer, Encik Ahmad developed cardiac arrest secondary to severe myocardial infarction and was not resuscitable. The nurse called the family members back to the ICU and told them that an unexpected event had occurred. They arrived not long after the ICU team ceased resuscitation and pronounced him dead.

Task: Explain to Puan Halimah and Adam what had occurred

Specific challenges in this scenario:

Adam distrusts the hospital in general. However, with Encik Ahmad's recovery, Adam is beginning to regain his trust. This unexpected turn of events is likely to rouse suspicion and spark a great deal of anger.

Issues to Consider	Possible Reactions	Suggested Responses
<ul style="list-style-type: none">• Prior distrust in the healthcare system• Breaking of unexpected bad news• Full disclosure• Anger management	<ul style="list-style-type: none">• Anger• Suspicion• Distrust• Demands full explanation	<ul style="list-style-type: none">• Break the news gently and sympathetically• Explain clearly the turn of events• Accept that anger is natural and let it occur• Show empathy

Possible dialogue:

Doctor : *I am afraid that something serious has happened. Your father's heart stopped suddenly. [pause] I am sorry, we were unable to save him.*

Adam : *What are you saying? [angry tone] He was fine when we left him.*

Doctor : *[neutral tone] Yes, he was stable and about to go to the ward...*

Adam : *...I can't accept this! [angry outburst]*

Doctor : *[silence]*

Adam : *Was this another mistake like what happened in the ward?*

Doctor : *No, it was not a mistake. [soothing tone] He suffered a massive heart attack. Yes, you are right, he was fine. In fact he was reading the newspaper when he complained of severe chest pain and collapsed. We tried to revive him for 30 minutes but he did not respond. I'm sorry your father has passed away.*

Doktor : *Minta maaf Encik Adam. Kami ada berita buruk. Ayah encik telah meninggal dunia akibat serangan jantung.*

Adam : *Maksud doktor? Kami baru sahaja melawat ayah. Ayah elok sahaja.*

Doktor : *Ya, memang dia stabil dan memang akan dipindahkan ke wad, tetapi....*

Adam : *...Saya tak boleh terima semua ini! [nada marah]*

Doktor : *[senyap]*

Adam : *Ini mesti silap lagi, macam dalam wad!*

Doktor : *[nada lembut] Encik, ini bukan kesilapan. Ayah encik mengalami serangan jantung yang teruk. Benar cakap encik, ayah stabil semasa ditinggalkan tadi, dia sedang membaca suratkhbar bila dia mengadu sakit dada dan terus tidak sedarkan diri. Kami cuba menyelamatkannya selama 30 minit tetapi dia tidak memberikan apa-apa tindakbalas. Maaf, ayah encik sudah meninggal dunia.*

Verbal responses to avoid:

"You know you are taking a risk when you signed the consent form."

"These things happen all the time."

"If it didn't happen now, it might happen in the ward."

"Puan kan tahu risiko semasa tandatangan borang keizinan"

"Sebenarnya serangan jantung biasa berlaku."

"Serangan ini boleh berlaku bila-bila masa, kalau tak di sini mungkin di dalam wad atau di rumah."

Case Study 2: Loss of Limb

Mr Chandra, a 46-year-old man was admitted with severe left lower limb pain. He had no prior hospitalisation and was diagnosed with acute critical limb ischaemia and gangrenous toes. He underwent an emergency femoropopliteal bypass on the day of admission. One week following surgery, he was admitted to ICU for severe sepsis. He needs non-invasive ventilation and vasopressors. The surgeon decides he needs an urgent below knee amputation. Neither the patient nor his wife is aware that the reason for his current deterioration is due to the ischaemic limb. The surgical opinion has not been conveyed to them.

Mr Chandra is a taxi driver. He is married with three school-going children and is the sole breadwinner.

Task: Inform Mr and Mrs Chandra of the need for amputation

Specific challenges in this scenario:

The clinician is meeting Mr and Mrs Chandra for the very first time. This first contact with them is to deliver the bad news. Time is crucial as Mr Chandra could die if surgery is delayed.

Issues to Consider	Possible Reactions	Suggested Responses
<ul style="list-style-type: none">• No time to establish rapport or trust• Breaking of bad news• Urgent decision-making	<ul style="list-style-type: none">• Distrust• Denial• Feeling pressured• Bargaining for time	<ul style="list-style-type: none">• Break the news gently and truthfully• Explain clearly the urgency and implications of the decision• Show empathy• Reduce or soften the emotional impact• Explore options available after losing a limb i.e. artificial limb• May require another meeting to discuss the matter

Possible dialogue:

Doctor : [concerned tone] *Mr Chandra, you know about the serious infection of your leg. [pause] The antibiotics have not worked. [pause] The infection has worsened. I am so sorry to tell you that we need to amputate that leg.*

Mr Chandra : [silence]

Mrs Chandra : *What do you mean doctor?*

Doctor : *Your husband has to undergo surgery to remove the infected leg to save his life.*

Mr Chandra : [long pause] [sigh] *Is there no other way?*

Doctor : *I am afraid this is the only option.*

Mr Chandra : *...but...when? Today?*

Doctor : *We need you to decide urgently. The infection has spread beyond the leg and has affected other organs. [pause] You can die if we delay the surgery.*

Mr Chandra : [silence][looks upset]

Doctor : *Would you both like some time alone to discuss this?*

Mrs Chandra : *But actually I am worried how we will manage at home.*

Doctor : *Would you like to discuss your concerns now?*

Doktor : [nada lembut] *Encik Chandra, saya ingin bincang mengenai jangkitan yang teruk di kaki ini. Antibiotik tak berkesan lagi. Jangkitan telah bertambah teruk. Kami terpaksa memotong kaki encik.*

Encik Chandra : [senyap]

Puan Chandra : *Maksud doktor?*

Doktor : *Jangkitan di kaki suami puan sudah melarat. Tidak ada cara lain untuk menyelamatkan nyawa Encik Chandra kecuali memotong kakinya.*

Encik Chandra : [senyap] [mengeluh] *Tidak ada cara lainkah doktor?*

Doktor : *Minta maaf, tapi tiada cara lain.*

Encik Chandra : *Er..Bila?..Sekarang?*

Doktor : *Ya, secepat mungkin. Jangkitan telah merebak ke organ-organ lain. Sebarang penangguhan boleh menyebabkan kematian.*

Encik Chandra : [senyap] [kelihatan risau]

Doktor : *Saya boleh beri masa untuk encik dan puan berbincang bersendirian dulu...*

Puan Chandra : *Sebenarnya, saya risau keadaan selepas pembedahan nanti.*

Doktor : *Sekiranya puan mahu, kita boleh bincang sekarang.*

Verbal responses to avoid:

“If you delay or refuse, you will have to bear the consequences.”

“You are just losing your leg.”

“If you refuse the operation, there is nothing else we can do.”

“Kalau encik tidak bersetuju, encik perlu tanggung risiko.”

“Encik kena buat pilihan, di antara nyawa atau kaki encik.”

“Jika encik tidak mahu tandatangan, kami tak dapat bantu lagi.”

“Encik patut rasa bersyukur, encik masih ada peluang hidup.”

CHAPTER 8: FOREGOING LIFE-SUSTAINING TREATMENT

End-of-life decision-making in the intensive care is a complex process that has enormous ramifications to the patient and family. Foregoing life-sustaining treatment is often discussed when intensive care therapy becomes potentially ineffective and burdensome to patients at the end of their lives. As most patients do not have decision-making capacity at this stage of their illness, this option of comfort care is frequently discussed with their families.

Decision-making on foregoing life-sustaining treatment should be regarded as a process, rather than an isolated event. Clinicians need to consciously consider this option and communicate early in the process of treating a patient with poor prognosis when death is a possible outcome. Acknowledging that treatment may fail can increase the trust between families and clinicians, thereby help create realistic expectations. However, if this option is discussed too soon without appreciating the family's perspective and acknowledging the emotional impact of the loss, conflict may ensue.

Principles of effective communication in foregoing life-sustaining treatment

1. Prepare for the meeting

A consensus on foregoing treatment by all teams managing the patient should be reached before the meeting as inconsistent communication causes confusion for families and impedes decision-making.

- A senior member of the team who has prior rapport with the family should conduct the meeting. He ought to examine his own personal feelings, attitudes and biases.
- The following information should be known prior to the meeting:
 - Patient's condition, treatment and prognosis. Review the charts and investigation results thoroughly.
 - The family's understanding of the patient's condition.
 - The family's concerns that have been expressed to other team members.

2. At the beginning of the meeting

- Allow introduction of all present and their roles or relationships to the patient.
- Be aware of anybody in the family, who is not the surrogate but exerts significant influence on decision-making.
- State the purpose of the meeting clearly.
“The purpose of the today’s meeting is to discuss further treatment plan for your father. He has not been progressing the way we hoped.”

3. Elicit family’s understanding

- Clarify what the family understands about the patient’s illness and current condition.
“Would you like to tell me what you know about your father’s condition so far.”
- Explain the current clinical situation. Provide information in a way that assures the family that every medically appropriate treatment option has been given but has failed.
“Your father has been in the ICU for seven days and he has not shown any improvement despite all the treatment provided from lung support, blood pressure support to dialysis.”

4. Elicit patient and family’s values and goals

- Recognise and respect the patient as an individual. This builds rapport and facilitates open communication.
“I can see this comes as a big shock to all of you, as just a week ago he was still driving his grandchildren to school.”
- Explore the patient’s wishes and values as well as family’s expectations, hopes and fears.
“If your father knows that continuing treatment will only prolong the dying process, what will he say?”
“Having heard of your father’s lack of progress in the last two weeks, what do you as a family expect?”
- Honour the patient’s wishes that has been communicated to his family or expressed in advance directive.
- Establish the extent of the family’s need for involvement in decision-making. Some families prefer to leave the decision-making to the treating clinician.

5. State recommendations clearly

- Provide the following information before recommending treatment option:
 - Underlying disease, complications and treatment provided.
 - Prognosis and realistic outcome.
 - Burden of treatment versus benefits and likelihood of achieving the desired goals.
 - Treatment options of comfort measures when discussing withdrawal or withholding life-support treatment.
- Convey the recommendation to forego life-sustaining treatment in a clear, straightforward manner. Use the word 'death' or 'dying' where appropriate.

"At this stage of his illness, continuing current treatment will only prolong the dying process. Based on medical consensus, I would like to suggest that we withdraw treatment."

"He's dying despite all treatment provided."
- Do not place undue burden of decision-making on the family before recommendations are made.

Avoid saying, *"Do you want everything to be done for your father?"* or *"What would you like us to do for him?"*
- Place emphasis on the disease process to deflect guilt or burden of decision-making on the family.

"Despite our best efforts, his blood pressure continues to drop. The infection is overwhelming and has caused many of his organs to fail."
- Reassure family that withdrawal of therapy does not mean abandonment of care. Explain comfort measures that will be given to control pain and other symptoms.

"The aim of treatment from now would be to relieve pain and discomfort. We will ensure that he is as comfortable as possible."

6. Address questions

- Ask the opinion of the family on the treatment recommendation.
“How do you feel about what I’ve told you?”
- Respond to specific questions.
- Be prepared to deal with requests for continuing treatment.
“Can you help me understand why you want these treatments continued.”
- Provide emotional support and listen carefully.

7. At the end of the meeting

- Summarise the major points discussed and reiterate the treatment recommendation to forego life-sustaining treatment.
- Ensure the family knows how to reach us for questions.
- Make referrals for psychological, emotional and spiritual support for the family, if necessary.

8. Document the meeting

Record the following information in the patient’s case notes:

- Those present at the meeting.
- Information relayed regarding the clinical status and its likely course.
- Treatment options discussed and recommended.
- Decisions reached and subsequent treatment and care to be provided.
- Outstanding issues that need further discussion.

Example of documentation:

I had a discussion with Mr Rajoo’s wife and his brothers, Mr Siva and Mr Rajah on further treatment plans. Also present were neurologist, Dr Tan TH and SN Siti Rokiah. The patient has not shown any improvement clinically and he remains unconscious despite sedatives being stopped for four days. His CT brain shows a massive right middle cerebral artery territory infarct. He is not expected to regain his mental function. Mrs Rajoo expressed that her husband would not have wanted to be dependent on anyone. The option of comfort care including terminal extubation was suggested. Mrs Rajoo was concerned that her husband will be ‘suffering’ following extubation. She was reassured that he will be comfortable on morphine infusion. The family had agreed to comfort care but requested for some time to break the news to Mr Rajoo’s elderly mother. In the event of deterioration, the family has agreed that there will be no escalation of treatment or CPR.

Case Study 3: Medically Inappropriate Care

Aisha, a 40-year-old mother of two, developed status asthmaticus at home and was found to be pulseless and cyanosed on arrival at the ED. Cardiopulmonary resuscitation was instituted and she had ROSC after 20 minutes. She was admitted to ICU and cerebral protected for 24 hours. From the outset, doctors have informed the family the likelihood of a poor neurological outcome. At 72 hours, Aisha’s neurological status remains poor, although she has spontaneous respiration. Her CT brain shows severe cerebral oedema with extensive areas of infarct while her EEG is consistent with severe encephalopathy. The neurologist confirms that her neurological prognosis is poor and she will be totally dependent on care should she survive. Aisha’s husband, Johan has been informed of her current condition and poor prognosis. He is however extremely hopeful for a recovery. He is adamant that all resuscitative measures be continued.

Task: Discuss with Johan that continuing medical therapy is no longer appropriate

Specific challenges in this scenario:

Johan cannot accept the medical facts as Aisha is young and well. He is optimistic of her full recovery and insistent that all active therapy be continued.

Issues to Consider	Possible Reactions	Suggested Responses
<ul style="list-style-type: none"> • Sudden and rapid deterioration • Poor prognosis versus family’s expectation • Patient’s values and wishes • Palliative care 	<ul style="list-style-type: none"> • Denial • Guilt • Persistence to continue • Helplessness • Overwhelmed 	<ul style="list-style-type: none"> • Explain the turn of events clearly • Inform the basis of poor prognosis • Focus on the patient’s values and preferences • Show empathy • Allocate some time for the family to think and decide • Frequent and consistent explanation on poor prognosis to deal with denial • Discuss the care of a comatose patient • May require further meetings to discuss the matter

Possible dialogue:

Doctor : [explains turn of events, lack of improvement and poor prognosis]
We have tried all appropriate treatment but [pause] I am so sorry to tell you that the damage to her brain is very severe. [pause] This is why she is still in a coma.

Johan : *So what are we going to do next?*

Doctor : *Because she has not responded to the treatment so far [pause] it is unlikely that continuing treatment will bring her out of her coma.*

Johan : *What do you mean?*

Doctor : *I mean that persisting with current treatment is of no benefit and therefore we should consider stopping treatment. [pause]*

Johan : *Which treatment?*

Doctor : *The breathing tube...we will remove the breathing tube...*

Johan : *What will happen then?*

Doctor : *She will continue to breathe on her own but we don't know for how long. Should she develop any breathing difficulties, we will not put the tube back. We will make sure that she is comfortable and be allowed to die.*

Johan : [worried tone] *But she is young and what about the children?*

Doctor : [leans forward] [soothing tone] *I can see that this is very difficult for you, Encik Johan.*

Johan : *I don't know, what can I do?*

Doctor : *You have done all you can, Encik Johan. You brought her to hospital as soon as possible [pause] and you have been by her side ever since.*

Johan : [silence]

Doctor : *What would Aisha have wanted if she knew she would remain comatose?*

Johan : *We have never discussed it, I'm confused.*

Doctor : *Do you want some time to think this over and perhaps discuss this with someone?*

Johan : [nods]

Doktor : [memberi penerangan tentang rawatan, keadaan pesakit dan prognosis yang tidak baik] *Kita telah berusaha sedaya upaya tetapi kerosakan pada otak Puan Aisha adalah terlalu serius sehingga rawatan tidak memberi kesan. Sebab itu Puan Aisha masih dalam koma.*

Johan : *Jadi, apa tindakan seterusnya?*

Doktor : *Oleh kerana Puan Aisha tidak memberikan tindakbalas positif setakat ini, meneruskan rawatan tidak mungkin menyedarkan dia dari koma.*

Johan : *Apa maksud, doktor?*

Doktor : *Saya berpendapat, sudah sampai masa kita fikirkan kemungkinan menghentikan rawatan.*

Johan : *Rawatan yang mana satu?*

Doktor : *Tiub pernafasan, kita akan keluarkan tiub...*

Johan : *Apakah yang akan berlaku selepas itu?*

Doktor : *Tiub pernafasan akan ditanggalkan. [senyap] Dia akan bernafas sendiri tetapi kami tidak dapat menjangka untuk berapa lama. Sekiranya dia mengalami kesukaran bernafas, kita akan memberi ubat agar dia selesa. Kita tidak akan letak kembali tiub pernafasan supaya dia boleh meninggal dalam keadaan tenang.*

Johan : *[nada sedih] Dia masih muda. Macam mana dengan anak-anak?*

Doktor : *[nada lembut] Ini memang sesuatu yang sukar...*

Johan : *Saya tak tahulah. [menggeleng] Apa yang boleh saya buat?*

Doktor : *Encik dah melakukan yang terbaik. Membawa isteri ke hospital secepat mungkin dan berada di sisinya selama ini.*

Johan : *[senyap]*

Doktor : *Apa yang encik rasa Aisha mahu sekiranya dia tahu dia tidak sedar dari koma?*

Johan : *[nada risau] Saya tak tahu...Saya bingung.*

Doktor : *Encik mungkin memerlukan sedikit masa untuk berfikir atau berbincang dengan ahli keluarga.*

Johan : *[angguk]*

Verbal responses to avoid:

"There is nothing more we can do for her. You need to decide soon."

"It is utterly futile to go on."

"It will be very difficult to care for someone in this state."

"Encik perlu membuat keputusan segera kerana tiada apa-apa bantuan yang dapat kami berikan lagi."

"Meneruskan rawatan adalah sia-sia sahaja."

"Pesakit koma memerlukan jagaan rapi sepenuh masa, ini akan membebankan keluarga."

Case Study 4: Brain Death

Mr Lim, a 66-year-old pensioner, has just been diagnosed to be brain dead, secondary to a subarachnoid haemorrhage that occurred three days earlier. His only next-of-kin is Lisa, his daughter who has just arrived from London. She has been informed over the phone by one of the doctors that his neurologic prognosis is poor and some confirmatory test is being conducted. She is devastated by the news. She is meeting the ICU doctors for the first time.

Task: Inform Lisa that her father is brain dead and the next line of management

Specific challenges in this scenario:

Lisa is exhausted from the travel and is stressed by the news. She may not have understood the earlier phone conversation or grasped the gravity of the situation. She is likely to feel isolated and may require emotional and psychological support.

Issues to Consider	Possible Reactions	Suggested Responses
<ul style="list-style-type: none">• Suddenness• Non-acceptance• Lack of rapport• Lack of family support• The concept of brain death	<ul style="list-style-type: none">• Guilt for being away• Denial• Lack of trust• Expecting miracles• Intense grief	<ul style="list-style-type: none">• Assess her current understanding of the situation• Explain results of clinical and imaging tests• Explain that brain death is death• Listen to her concerns and show empathy• Use silence appropriately• Provide support• Avoid discussion of organ donation until death is well accepted and understood

Possible dialogue:

Doctor : *May I know what they told you over the phone about your father's condition?*

Lisa : *I was told that he had a very bad bleed in his brain and that his condition has worsened.*

Doctor : *Yes , that is right. We carried out further test to check his brain function. [pause] [gentle tone] I am sorry to tell you that the results show that he is brain dead.*

Lisa : *Brain dead?? [disbelief] Doctor, my father is still breathing and... and he feels warm.*

Doctor : *Yes, Lisa [pause] Although he appears to be 'alive' and breathing, it is only because of the machine. Once we take him off the machine his heart will eventually stop.*

Lisa : *But people have come out of coma before... What exactly is this test?*

Doctor : *This is a standard test done all over the world to examine the brain stem. The brain stem controls the vital functions of the brain. The test assesses the ability to breathe, to swallow and other reflexes like the eye reflex.*

Lisa : *[nods]*

Doctor : *The test we just carried out on your father confirms that his brain stem is not functioning.[pause] [gentle tone] His brain is dead and being brain dead is equivalent to death.*

Lisa : *I just got here...I didn't have time to be with him...[weeps]*

Doctor : *[leans forward] [gentle tone] I am so sorry but no one would have been able to predict this. It may be comforting for you to know that he did not suffer. Is there anyone that we can call for you?*

Doktor : *Pihak hospital ada menelefon cik, kan? Boleh beritahu saya apa mereka beritahu cik mengenai keadaan ayah?*

Lisa : *Saya diberitahu ayah mempunyai pendarahan yang teruk di dalam otak dan keadaannya semakin serius .*

Doktor : *Ya, benar. Kami telah menjalankan ujian untuk melihat fungsi otak. [senyap] [nada lembut] Malangnya keputusan ujian menunjukkan otak tidak berfungsi lagi, otak sudah mati.*

Lisa : *Otak sudah mati?? [nada tinggi] Doktor, ayah saya masih bernafas lagi...dan badanya rasa panas lagi.*

- Doktor : *Ya, cik. [senyap] Walaupun dia kelihatan 'hidup' dan masih bernafas, ini kerana bantuan mesin. Selepas mesin dicabut, akhirnya jantung akan berhenti juga.*
- Lisa : *Tapi ada orang yang dalam koma yang telah sedar semula... Ujian apa semua ini?*
- Doktor : *Ujian ini adalah ujian standard yang dilakukan di seluruh dunia untuk memeriksa fungsi pangkal otak. Pangkal otak adalah bahagian otak yang mengawal semua fungsi utama otak. Ujian ini menguji tindakbalas yang dikawal oleh otak seperti kebolehan bernafas, menelan dan tidakbalas anak mata.*
- Lisa : *[angguk]*
- Doktor : *Ujian yang baru kami jalankan ke atas ayah cik mengesahkan yang pangkal otaknya tidak berfungsi. [senyap] [nada lembut] Cik, otaknya sudah mati dan ini sama seperti dia telah meninggal dunia.*
- Lisa : *Saya baru sahaja sampai...Tak sempat nak bersama ayah. [menangis]*
- Doktor : *[nada lembut] Cik, tiada siapa yang dapat menduga perkara sebegini boleh berlaku. Ia berlaku secara tiba-tiba dan ayah cik tidak merasa sakit. Ada sesiapa yang kami boleh tolong hubungi untuk cik?*

Verbal responses to avoid:

"You just have to accept that by law he is dead and we have no obligation to continue."

"We are going to switch off the ventilator whether you agree or not."

"Yes, he is still alive but the brain is dead."

"Otak sudah rosak, tapi nyawa masih ada."

"Walaubagaimanapun, dari segi undang-undang dia sudah meninggal dunia."

"Mesin pernafasan akan diberhentikan samada anda setuju atau tidak."

Case Study 5: Prolonged ICU Stay

Mr Alias, a 50-year-old security guard, underwent a laparotomy for perforated duodenal ulcer. He was admitted into ICU post-operatively with septic shock. Unfortunately his stay is complicated by recurrent episodes of intrabdominal sepsis requiring four relaparotomies. At day 58 of ICU stay, he remains anuric and is on total parenteral nutrition. Despite being tracheostomised, there is difficulty weaning him off mechanical ventilation

Task: Clarify Mr Alias' family expectations. Inform them that the overall prognosis is poor and discuss the option of palliative care in the event of further deterioration

Specific challenges in this scenario:

Clinicians may find it difficult to discuss care plans in the event of deterioration because the patient had 'pulled through' the last few episodes of severe sepsis. They may have developed an attachment to the patient and family. The family perceives Mr Alias' overcoming each episode of sepsis as a sign that he is a 'fighter' and therefore will not be receptive to palliative care.

Issues to Consider	Possible Reactions	Suggested Responses
<p>Clinician</p> <ul style="list-style-type: none"> • Inadequate communication on palliative care options • Prognosticating poor outcome • Perception of failure <p>Family</p> <ul style="list-style-type: none"> • Poor outcome versus family expectation • Differing expectations • Conflict on treatment options 	<ul style="list-style-type: none"> • Attachment • Uneasiness • Fear of being perceived as giving up <ul style="list-style-type: none"> • Hopefulness • Disbelief • Fear of abandonment • Bargaining 	<ul style="list-style-type: none"> • Obtain medical consensus prior to discussion with the family • Understand how they view the overall treatment provided • Discuss their expectations • Guide them to understand how palliative care option was arrived at • Follow up on the conversation to allow them time to think over • May need a few meetings to address this issue

Possible dialogue:

Doctor : [course of events during the prolonged ICU stay with periods of deterioration has been explained] *We need to discuss how we should provide the best care for Encik Alias should he deteriorate again.*

Family : *We should continue with whatever we are doing since he does come out of his 'bad' days. Right?*

Doctor : *Do you expect your father to get better?*

Family : *Yes, we think he will be back home for Hari Raya.*

Doctor : *We have been treating him all this while as we thought we could cure his illness. However, despite almost two months of intensive treatment he remains very ill. [pause] Should he get worse again, we suggest not to restart his blood pressure medication or perform CPR.*

Family : *You mean if things get worse, we will not do anything? [disbelief] How can you just sit and watch?*

Doctor : *We don't think that restarting his blood pressure medication will benefit him as the infection in his gut cannot be controlled. [pause] In our honest opinion, despite treatment, he will die because of his illness.*

Family : *How can we do nothing?*

Doctor : [leans forward] [gentle tone] *Of course not, we will continue caring for him. [pause] Although we cannot cure his illness. We will still care for him, make sure he is not in pain and help to keep him comfortable.*

Doktor : [dokter menerangkan keadaan pesakit dan tahap kesihatan yang semakin merosot] *Kita perlu berbincang mengenai jagaan terbaik untuk Encik Alias bila keadaannya merosot sekali lagi..*

Keluarga : *Kita patut teruskan rawatan, kan doktor? Keadaan dia tak tentu, ada hari dia sihat, ada hari dia teruk, bukan begitu doktor?*

Doktor : *Adakah encik mengharap ayah akan kembali pulih?*

Keluarga : *Ya, kami harap dia dapat pulang untuk berhari raya di rumah.*

Doktor : *Sebenarnya kami merawat ayah encik selama ini kerana kami sangka penyakitnya ada harapan sembuh. Tetapi setelah dua bulan dalam jagaan intensif, kesihatan ayah encik masih dalam keadaan yang sangat serius. Sekiranya keadaan Encik Alias bertambah kritikal, kami mencadangkan agar dia tidak diberi ubat tekanan darah atau rawatan CPR.*

Keluarga : *Maksud doktor, kalau keadaan ayah bertambah teruk, doktor tak akan buat apa-apa? Tak kan kita nak biarkan ayah begitu saja?*
[nada terkejut]

Doktor : *Memberi ubat untuk tekanan darah tidak akan membantu lagi selagi jangkitan di dalam perut tidak terkawal. Minta maaf tetapi terus terang saya katakan, lambat laun ayah encik akan meninggal disebabkan penyakit yang dihidapi.*

Keluarga : [senyap]

Doktor : [nada lembut] *Walaupun kita tak boleh merawat penyakitnya, kita akan terus memastikan ayah encik tidak merasa sakit dan berada dalam keadaan selesa.*

Verbal responses to avoid:

“Don’t you realise he is just getting from bad to worse.”

“Well, we can go on and on but that would be pointless.”

“Think about what you are doing to your father and the suffering that we are inflicting on him.”

“Sebenarnya rawatan intensif adalah sia-sia sahaja.”

“Kamu semua tidak sedarkah keadaan ayah semakin teruk?”

“Fikirkan akibat keputusan kita yang hanya akan membuat ayah menderita.”

CHAPTER 9: MANAGING CONFLICTS

Conflict occurs when there is inability to arrive at a consensus on management decisions, goals of care and the extent of therapy to be instituted or withheld. Whilst every effort should be made to maintain a trusting relationship, conflicts may be inevitable. It is the healthcare professional's responsibility to commit to a resolution and settle it above vested interest.

Conflicts occur as a result of:

- Inadequate understanding of the situation due to insufficient, confusing or inconsistent information.
- Poor communication.
- Differing viewpoints or expectations.
- Feelings of guilt, fear or distrust.
- Different religious and cultural backgrounds.

Conflicts may occur among healthcare professionals when multiple teams are involved. It is best to achieve consensus on management issues prior to discussing with families. This is especially pertinent when discussing treatment goals and limitation of therapy.

If conflicts are not resolved in a satisfactory manner, the consequences are:

- Patients suffer undue pain and distress.
- Families are left feeling angry and guilty. This may be long lasting, resulting in complicated bereavement.
- Healthcare professionals may experience moral distress and disillusionment.
- For all involved, it is draining, time consuming, stressful and costly.

Negotiation is a process to aid resolution of conflict. Efforts should be made to clarify, not justify positions and to find common grounds to develop mutually acceptable solutions. Sound communication skills not only convey facts adequately but are responsive to emotions and needs. The three steps involved are:

1. Understand the fundamental problem

- Be aware of one's own role in contributing to the conflict. Healthcare professionals need to examine their biases or perceptions towards the family. For example, they may:
 - Perceive the family as difficult or annoying.
 - Feel like this is a power struggle.
 - Feel demoralised or a failure.
- Avoid attributing blame to those involved. Do not label family as ignorant or other healthcare professionals as unreasonably optimistic when they do not accept the suggested treatment plan.
- Identify and stay focused on the problem. For example, in cases of medical futility, the issue of CPR not benefitting the patient should be the focus of discussion, rather than the family's unrealistic expectations.

2. Analyse and understand the competing interest in the matter

- Have an open and honest discussion to establish early rapport and trust.
- Listen carefully to indicate genuine interest in the other party's perspectives, frustrations and fears.
- Explore any unspoken concerns by using open-ended questions.
 - "Explain to me how you see the situation now."*
 - "I encourage you to share with me your thoughts on ..."*
- Check understanding of the clinical situation to ensure shared expectation of treatment is met.
 - "Please tell me what you think the outcome of this illness will be so that I can better understand."*
- In cases of withdrawal/withholding of treatment, avoid harping on futility. It encourages power struggle and belittles the other party.
- Understand cultural and spiritual beliefs. Be aware that others may view the illness as a test of faith.
 - "I understand that you are hoping for a miracle. However, we must prepare for the worst."*

- Address prior misunderstanding and previous bad experience with the healthcare system.
 - Acknowledge previous experience
 - “I am sorry you feel this way about things, how can we make it better for you.”*
 - “Thank you for bringing this to our attention.”*
- Overcome the reluctance to engage in further communication even though hostility is sensed.
- Stay calm, accept the anger and respond visibly through silent communication by nodding and appropriate eye contact. Keep tone and content neutral.
- Express empathy and compassion.
 - “I sense that this is frustrating and overwhelming for you.”*
 - “Anyone receiving this news will be devastated.”*

3. Work on a solution

- Find a common ground. Avoid focusing on differences.
 - “We share the same goals. I can see you want the best for the patient. We also want to provide appropriate medical care for him.”*
- Establish mutual respect by acknowledging concerns.
- Set clear goals for evaluation, e.g. when considering time-limited trial of interventions.
 - “We will continue on these high doses of drugs to support his BP for another 48 hours. If his BP remains low, this would indicate that the drugs are not working and we will withdraw treatment.”*
- Provide objective information to substantiate your recommendations.
 - “The chance of survival in patients with out-of-hospital cardiac arrest is only 5%.”*
- Get assistance from individuals uninvolved in the conflict to provide a neutral platform e.g. social workers, religious figures or other healthcare professionals.

Case Study 6: Conflict with Family

Encik Yusof, a 71-year-old man, has advanced chronic obstructive airways disease. He had multiple ICU admissions and was ventilated twice in the last seven months. In the last three years, his quality of life has deteriorated. He is now housebound, dependent and needs home oxygen. In the last admission, there was a discussion between Encik Yusof, his wife and his respiratory physician, Dr Ali that in the event of further deterioration, intubation and CPR will not be performed. Instead, palliative treatment will be offered. This conversation was documented in the case notes.

Encik Yusof is admitted again for worsening shortness of breath. Despite non-invasive ventilation, he is dyspnoeic and increasingly drowsy. Palliative care is instituted. However, his daughter, Zara who lives with him, is upset and angry that her father is not admitted to the ICU. She is unaware of the previous discussion and has just been informed about it. She does not think her parents understood the implications of their decision. She becomes increasingly agitated as her father deteriorates. The intensive care team is asked to assist in this situation.

Task: Talk to Zara and guide her to accept her father's advance care plan

Specific challenges in this scenario:

There is conflict between Zara and the physician's current management plan which concurs with the advance care plans of her father. She is feeling upset as she was not included in the discussion and she cannot accept her father's decision.

Issues to Consider	Possible Reactions	Suggested Responses
<ul style="list-style-type: none"> • Lack of information • Lack of understanding • Non-acceptance • Palliative care 	<ul style="list-style-type: none"> • Distress • Guilt • Anger • Distrust 	<ul style="list-style-type: none"> • Explain how the decision on limitation was made • Include her mother and the medical team involved in the previous discussion • Clarify misinformation to help her come to terms with her father's terminal illness • Reaffirm that the care plan honours her father's wish • Avoid dwelling on the documentation • Do not neglect her needs e.g. fear • Reassure that comfort care will continue

Possible dialogue:

Doctor : *What do you understand of your father's condition?*

Zara : [angry tone] *He is struggling to breathe and the doctors tell me he cannot be admitted into the ICU because he said he didn't want to. That can't be true.*

Doctor : [gentle tone] [slow pace] *The last time, your parents had a conversation with the doctor looking after his lungs, Dr Ali, your father was clear about his deteriorating condition and does not want further intensive treatment.*

Zara : *Are you telling me to just leave him here to die. I find this unacceptable. Where is this Dr Ali now?*

Doctor : *We will try and call him now. I see that this is hard for you but this is what your father had wanted for himself. [pause] [maintains eye contact] All of us wish that our parents will be with us always but in his situation it would be best not to intervene.*

Zara : *But he can't breathe [sobs] I feel so helpless, like I am neglecting him.*

Doctor : *We will continue to care for your father till the end. We have promised him we will give him medication to keep him comfortable.*

Zara : [raises voice] *But I still want you to intubate and give him another chance.*

Mother: [puts hand on Zara's shoulder] *This is what your father wants.*

- Doktor : *Apa yang cik faham tentang keadaan bapa cik?*
- Zara : *Sekarang ayah sesak nafas. Doktor beritahu saya dia tidak akan diberi rawatan intensif kerana ini yang ayah hendak. [marah] Saya tidak boleh percaya.*
- Doktor : *Kali terakhir ayah masuk hospital, dia dan emak telah berbincang dengan pakar paru-paru, Dr Ali. Bapa cik sedar keadaannya semakin merosot. Dia yang mengambil keputusan untuk tidak lagi diberi rawatan intensif.*
- Zara : *Macam mana ini. Tak kan doktor nak biarkan dia sahaja macam ni. Saya tak boleh terima.*
- Doktor : *Cik, saya sedar sangat sukar nak terima kenyataan ini tetapi ini yang ayah cik mahukan untuk dirinya. [senyap] Kita semua memang harap ibu dan ayah kita akan sentiasa bersama kita tetapi untuk beri rawatan intensif sekali lagi tak akan memberi manfaat. Dalam keadaan ini adalah lebih baik sekiranya kita menurut kehendak ayah cik.*
- Zara : *Tetapi dia tak boleh nafas. [menangis] Saya rasa bersalah mengabaikan ayah.*
- Doktor : *Cik tidak mengabaikan ayah. Kita masih memberi rawatan kepada Encik Yusof. Kita dah berjanji dengan dia, bila tiba masanya, kami akan memastikan dia selesa.*
- Zara : *[suara tinggi] Tapi saya nak doktor masukkan tiub dan berikan satu lagi peluang untuk ayah.*
- Ibu : *[letak tangan di bahu Zara] Zara, ini kehendak ayah.*

Verbal responses to avoid:

“Can’t you see he is getting worse with time?”

“There is nothing more we can do.”

“You can’t go against your father’s wishes.”

“It has already been decided.”

“The decision is legal and clearly documented.”

“Cik mesti sedar yang keadaan dia semakin merosot.”

“Kami tidak boleh melakukan apa-apa lagi.”

“Cik tidak boleh menidakkan kehendak ayah cik.”

“Keputusan telah dibuat dan telah direkodkan, segalanya mengikut prosedur.”

Case Study 7: Conflict with Other Healthcare Professional

Mrs Lee, a 47-year-old lady, has ESRF since the age of 30. She had a renal transplant and was dialysis free for 12 years. However, she developed chronic rejection and has been dialysis dependent for the last four years. She was admitted and treated for pneumonia. She was due to be discharged when she was found unconscious in the ward. Cardiopulmonary resuscitation was commenced with ROSC after 10 minutes. Her CT brain showed a massive intracranial bleed and she underwent a craniotomy with removal of clot. She was admitted to ICU following surgery.

One week after surgery, her neurological state remains poor. A repeat CT brain shows some residual bleed with mild cerebral oedema. An EEG done is consistent with severe encephalopathy. The intensivist plans for withdrawal of treatment but the nephrologist in-charge, Dr Hashim, disagrees. He wants all treatment to be continued including performing a tracheostomy. He feels that more time is needed before deciding that the overall prognosis is poor.

Task: Discuss with Dr Hashim on the appropriate direction of care

Specific challenges in this scenario:

There is a difference in opinion between two clinicians on the direction of care. They need to negotiate and come to an agreement before the direction of care is presented to the family. This must be done in the patient's best interest.

Issues to Consider	Possible Reactions	Suggested Responses
<ul style="list-style-type: none"> • Differing viewpoints on direction of care • Differing expectations of recovery • Attachment 	<ul style="list-style-type: none"> • Disbelief • Non-acceptance • Bargaining • Over-protective 	<ul style="list-style-type: none"> • Be mindful of personal negative feelings affecting interaction and promoting hostility • Reaffirm and acknowledge that the nephrologist has provided optimal care • Negotiate and agree on the direction of care in the best interest of the patient • Provide medical evidence to support poor prognosis • Consult an independent third party i.e. neurologist • Discuss family preferences • Discuss implications of differing direction of care • May require further meetings to discuss the matter

Possible dialogue:

Intensivist : [friendly tone] *Dr Hashim, thank you for coming to discuss on further treatment plan for Mrs Lee. I realise that you have taken care of Mrs Lee for many years and have looked after her very well.*

Nephrologist : *Yes, I have been her nephrologist since she was diagnosed with end stage kidney disease. I know her very well and she is not a person who will give up easily.*

- Intensivist : *But Dr Hashim, Mrs Lee's neurological recovery has been poor. Her GCS has not improved. It remains at four from the time her sedation was weaned off one week ago. I suggest we start discussing with her family on withdrawal of therapy.*
- Nephrologist : *No. I am not comfortable with the decision. We have not given her enough time. [raises voice] Get a tracheostomy done for her.*
- Intensivist : *Dr Hashim, the tracheostomy is not going to benefit her. Clinically she has not made any neurological recovery and her EEG showed severe encephalopathy. What are your expectations of her outcome?*
- Nephrologist : *I don't see any problem here. With the tracheostomy, she can be weaned off the ventilator. She just needs the time. Just continue with the current management. We can discuss this again later. Why the hurry?*
- Intensivist : *[neutral tone] It is not about the tracheostomy. I understand you're hoping for a positive outcome but her neurological recovery is expected to be poor. She will likely be in a persistent vegetative state, even if she can be weaned off the ventilator. [pause] [gentle tone] Do you have any thoughts on her family's preferences?*
- Nephrologist : *Erm.. No, I've not discussed this with her husband.*
- Intensivist : *We need to come to a decision on what is best for Mrs Lee as quickly as possible because her family needs to know the direction of care. Can I suggest we seek the opinion of the neurologist on the prognostication?*
- Nephrologist : *Alright. We'll talk again after that.*

Verbal responses to avoid:

"You need to let go."

"Withdrawal is the only option..."

"She will die regardless of what we do..."

CHAPTER 10: CRITICAL INCIDENTS

Dealing with critical incidents

Critical incidents are defined as events or situations ‘that have sufficient emotional power to overcome the usual coping abilities of people working in environments where some degree of exposure is expected’ (Mitchell & Bray, 1990). In medicine, these events may include unanticipated adverse patient event, medical error, or patient-related injury or death, which may or may not be preventable. Healthcare professionals involved in the critical incident may be traumatised by the event. Debriefing and defusing are techniques used to provide closure, alleviate signs and symptoms of acute distress and restore the individuals involved to their usual state of health.

Debriefing and defusing are supportive, crisis-focused discussions of a critical incident, ideally conducted by trained facilitators. Debriefing is conducted to allow deeper reflection on thoughts, symptoms and emotions, with a larger group within three to five days of the incident. Defusing, on the other hand, is conducted as soon as possible to reduce the intense reactions to a traumatic event quickly, to prevent misinterpretation of one’s emotions and to facilitate return to normal duties.

A communication plan is key to conducting effective defusing and debriefing sessions. In the intensive care setting, defusing may be more applicable. This process encompasses three broad segments namely Introduction, Exploration and Information.

Introduction

- Conduct the session in a private and neutral environment e.g. seminar room as opposed to the consultant’s office.
- Introduce all present.
- State the purpose of the meeting that is to assist individuals involved in returning to routine functions after the incident.
- Emphasize that it is not an investigation of the incident.
- Ensure confidentiality.

Exploration

- Set the tone as conversational and informal.
- Encourage participation as much as possible. Be open and honest.
- Begin by asking participants to describe the incident briefly. Guide them to focus only on what they did.
 - “Please describe what you did during the incident?”
 - “Can you give a brief overview of what happened?”
- Encourage participants to describe their thoughts and emotions. Recall physical symptoms (e.g. tremors, sweating, palpitations) during the event.
 - “How did you feel when it happened?”
 - “Personally for you, what was the worst thing?”
 - “What disturbs you the most about the event?”
 - “What symptoms are you currently experiencing?”
- Restate the key phrase to check accuracy and to provide assurance.
 - Junior doctor : *I feel so horrible. I want to quit.* [sobs]
 - Senior doctor : *So, you are feeling horrible and want to quit.* [nods]
 - Junior doctor : [nods]
- Allow silence.
- Summarise the discussion.

Information

- Assure the participants that their reactions are normal.
- Provide information on how to seek further support e.g. counseling.
- Provide some practical stress coping skills.
- Answer questions.

Case Study 8: Medical Misadventure

Mr Tan, a 58-year-old gentleman was admitted to ICU with septic shock from pneumonia. He was intubated by the medical officer, Dr Asnita who proceeded to insert a central line. Three attempts were made before successful insertion of the line. A chest x-ray following intubation and line insertion was performed. Soon after, Mr Tan developed progressive hypotension and hypoxaemia requiring escalating inotropes and ventilator requirements. Dr Asnita was informed of the rapid deterioration and had attributed this to the severe pneumonia. Over the ensuing 15 minutes, the patient developed cardiac arrest and was not resuscitable. The chest x-ray revealed a large pneumothorax on the side of the central line insertion. She is distressed as she realises that the patient had a cardiac arrest because of the missed tension pneumothorax.

Task: Talk to Dr Asnita about the critical incident

Specific challenges in this scenario:

The doctor did not suspect the pneumothorax and now feels guilty that this has resulted in the death of the patient. She is distressed and frightened of the repercussions.

Issues to Consider	Possible Reactions	Suggested Responses
<ul style="list-style-type: none"> • Feeling incompetent • Inability to continue working • Lack of training or supervision • Disclosure to family 	<ul style="list-style-type: none"> • Distress • Guilt • Frightened and traumatised • Shame and inadequacy • Loss of confidence • Physical symptoms e.g. sweating, shaking, feeling faint. 	<ul style="list-style-type: none"> • Initiate a private meeting as soon as possible • Go through the events • Encourage expression of thoughts and emotions • Highlight positive points e.g. immediate attendance following deterioration • Assure her that she will not be the one to inform the family at this time • Offer time off work • Offer further emotional support e.g. counselling • May require further meetings to discuss the matter

Possible dialogue:

Specialist : *Asnita, can you tell me what happened?*

Dr Asnita : [silence] [starts to weep]

Specialist : [offers tissue and leans forward] [gentle tone] *Asnita, don't be frightened, tell me what happened. I am here to listen.*

Dr Asnita : [relates the incident] *...I feel guilty for not detecting the pneumothorax. He died because of my mistake.*

Specialist : [silence] *Is that how you feel about yourself now, guilty?*

Dr Asnita : [shaky voice] *Yes and honestly I really want to quit all this now. And the family, what will I tell them?*

Specialist : *Would you like to meet the family?*

Dr Asnita : *I dare not face them now.*

Specialist : [reassuring tone] *Don't worry, I will talk to them when they arrive. Any doctor in your situation will feel like this. It is okay to have these thoughts. Why don't you take two days off and we can meet again when you get back.*

Verbal responses to avoid:

"How could you make such a mistake and not thought of a pneumothorax?"

"You cannot work in an intensive care if you can't even manage an obvious diagnosis."

"Let's hope Mr Tan didn't die in vain and you have learnt from this."

Case Study 9: Needlestick Injury

Dr Ng inserted a central line for an intravenous drug abuser admitted in septic shock. Following insertion, he was seen placing the sharps into the sharp bin. Murni, a junior staff nurse who is seven months pregnant, proceeded to clear the central line tray that had drapes on them. While clearing, the drapes she pricked her finger with a needle that was inadvertently left between the drapes. She quickly washed her finger under running water and informed the nursing sister who ensured the protocol for post needlestick injury was followed. She remained extremely distraught and was crying.

Task: Discuss the incident with SN Murni

Specific challenges in this scenario:

SN Murni is extremely upset over the incident given the uncertainty surrounding the patient's infective status and the implications to herself and her baby. She blames the doctor for his carelessness.

Issues to Consider	Possible Reactions	Suggested Responses
<ul style="list-style-type: none"> • Uncertainty of the future • Blaming others • Contemplating change of work environment 	<ul style="list-style-type: none"> • Distress • Anger • Fear • Worry • Helplessness • Numbness • Physical symptoms e.g. tremors, palpitations, nausea 	<ul style="list-style-type: none"> • Listen with empathy • Establish the facts • Encourage sharing of feelings and thoughts • Ask her to recall physical symptoms • Reassure her reactions and physical symptoms are normal • Offer support • Reassure that the process of handling sharps will be reinforced • May require further meetings to discuss the matter

Possible dialogue:

- Nursing sister : *Would you like to tell me what happened this morning?*
Murni : *I was clearing the central line tray when I pricked myself with a needle. I don't know how this could have happened as I saw the doctor clearing the sharps away. I quickly washed my finger but I am honestly very scared as I am pregnant and the patient is an intravenous drug abuser.*
Nursing sister : *[gentle tone] I am so sorry this happened. [pause] It's normal to feel frightened and anxious about the future.*
Murni : *Why didn't he remove the needle? He was so careless. [angry tone]*
Nursing sister : *Are you feeling really angry about this? I assure you that the procedure for handling sharps will be reinforced to all doctors.*
Murni : *[nods] I don't know what to do. What about my baby?*
Nursing sister : *[consoles her] Let's do the screening test for the patient first. Why don't you take some time off. Lets meet again after the result is back.*

- Ketua Jururawat : *Boleh beritahu saya apa yang terjadi pagi tadi?*
Murni : *Saya sedang membersihkan 'central line tray' bila jari saya tercucuk jarum suntikan. Saya tak tahu macam mana ni boleh berlaku sebab saya nampak doktor membuangkannya tadi. Saya cepat-cepat basuh jari saya tapi saya takut sangat sebab saya mengandung dan pesakit tadi seorang penagih.*
Ketua Jururawat : *[nada lembut] Saya turut rasa kesal dengan apa yang telah berlaku. [diam] Memang normal untuk rasa takut dan bimbang tentang kemungkinan akan terjadi.*
Murni : *Kenapa dia tak buang jarum tu? Dia sangat cuai! [nada marah]*
Ketua Jururawat : *Murni berasa marah dengan apa yang telah berlaku? Saya memberi jaminan yang prosedur mengendalikan jarum suntikan akan diperkukuhkan lagi dikalangan doktor.*
Murni : *[angguk] Saya tak tahu apa nak buat. Macam mana dengan kandungan saya?*

Ketua Jururawat: *Kita akan lakukan ujian saringan untuk pesakit tu dulu. Murni, boleh ambil cuti rehat. Nanti kita jumpa lagi selepas keputusan ujian diterima.*

Verbal responses to avoid:

"You should have been more careful."

"It was the doctor's fault. He should have removed all the sharps."

"Don't worry, it will be okay."

"This could have happened to anyone."

"Sepatutnya awak lebih berhati-hati."

"Ini memang salah doktor, sepatutnya dia buang semua jarum suntikan."

"Jangan risau, tak ada yang perlu dibimbangkan."

"Ini boleh terjadi kepada sesiapa sahaja."

CHAPTER 11: THE FINAL HOURS

For the patients in ICU, the end-of-life period may last from a matter of hours to days. When this becomes apparent or when the decision to forego medical treatment has been made, a thorough discussion with the family members on pertinent issues should follow. Every effort should be made to honour the patient's wishes.

During this crucial period, effective communication is of utmost importance. For those who provide care, they only have one chance to do it right. If it is carried out well, significant personal and family growth may follow. On the contrary, if done poorly, closure may be incomplete, suffering may occur, and bereavement may be difficult and prolonged. Careful management will lead to a smooth passage for the patient.

Before death

During the final hours, the following issues need to be addressed.

1. Timing of withdrawal of treatment

- Seek family's preference e.g. the family may want to wait for a close relative to arrive.
- Allow flexibility whenever possible.

2. Social or religious needs

- Enquire if there are any other family members that need to be present.
- Address issues on the presence of young children.
- Inform the family that their presence during the withdrawal process is entirely up to them.
- Reassure that the patient will not be left alone.
- Assist with religious needs whenever possible.

3. Option of dying at home

Some patients prefer to die at home. Every effort should be made to facilitate this. Symptom management at home needs to be addressed.

From the words of the wife of a patient with chronic heart failure who was allowed to die at home. (JICCN 2012)

"I know we did the right thing because I saw his face when he was finally at home with me, the kids and the dog, and it didn't matter that he only had a few days there, it was enough. I can't stress enough how grateful I and the whole family are to the individual practitioners and all the teams in the hospital and the community who worked together so hard to achieve Les' 'good death.'"

4. The actual process of withdrawing treatment

- Start by giving assurance.

"I want you to be assured that your mother will be pain free throughout this process."

- Explain the process in simple terms.

"After everyone has seen Puan Hasnah and said your prayers, we will remove her breathing tube and she will breathe on her own. We will also start a medication that will help keep her comfortable."

- Make clear again that death is the expected outcome.

"You understand that by removing the breathing tube she will be allowed to die naturally because of her illness."

- Be mindful of the words used as the wrong ones may incite guilt.

Say *"She will not breathe on her own for long due to her terminal condition"* instead of *"She will die after stopping therapy."*

The latter sentence may imply that death was due to the cessation of therapy as opposed to the natural progression of the illness.

5. The dying process

- Assess expectations and address fear as not many have witnessed death.

"Do you have any worries?"

- Explain the dying process if the family wants to know. The explanation may include secretions, noisy and irregular breathing, slowing of heart rate and its eventual stop.

- Reassure that any distress will be attended to promptly and that the 'sounds' they hear do not mean that the patient is suffering.

- Reiterate that one cannot predict the exact duration of this process.
“After the medications that maintain his blood pressure are stopped, I expect Mr Rajah to die from his illness. In my experience, though I cannot be certain, it is likely to be minutes to hours, instead of days.”
- Reassure families that they may be with the patient as they wish.

At the moment of death

- Pronunciation of death should be done promptly. Inform the family immediately.
“Your mother has died. I am sorry for your loss.”
- Console with appropriate non-verbal cues e.g. an arm around the shoulder, a hug or a gentle pat.
- Remain silent after pronouncing death. Anticipate and allow strong emotions.

After death

Some family members and caregivers draw comfort from taking time to talk, pray and say their last goodbyes before proceeding with final arrangements. Give them that time and privacy.

- Allow family to participate in the last office, if they wish.
- Be ready with information pertaining to handling of deceased body and other administrative matters.
- Identify family members who may have problems coping and refer for counselling.
- Encourage the family to call if they require further support.

Case Study 10: Last Office

Ms Tan, a 50-year-old lady, diagnosed with advanced carcinoma of the uterus was admitted to the ICU for severe pneumonia. She did not respond to therapy after three days of intensive care. A family conference was held with her brother and niece who are her next-of-kin. It was decided that treatment was to be withdrawn and palliative care instituted. Her niece, Jenny requests to be with her in her final hours and participate in her care after death.

Task: Identify the patient and family's wishes and needs. Facilitate towards the family's ideals of a good death

Specific challenges in this scenario:

Clinicians need to make an effort to accommodate the family's special request to participate in the last office. Nurses need to be mindful of Jenny's presence and guide her through the process.

Issues to Consider	Possible Reactions	Suggested Responses
<ul style="list-style-type: none">• Never witnessed the dying process• Not knowing what to expect• Allow family to regain control• Need to provide a good death	<ul style="list-style-type: none">• Fear• Worry• Feeling uncertain• Helplessness• Overwhelmed	<ul style="list-style-type: none">• Listen to the family's concern• Explain the process of dying• Facilitate the family to carry out the care after death• Seek to understand and address cultural and spiritual needs

Possible dialogue:

Jenny : *Will she be in pain?*

Doctor : *No. We will make every effort to keep her comfortable till the end. We will provide her with pain relief.*

Jenny : *Can I sit here and be with her?*

Doctor : *Yes, of course. You can be by her side and say your prayers if you wish.*

Jenny : *What will happen after she dies? Can I help in the care?*

Doctor : *And yes if you want, you can help the nurses and carry out the care after death. [The doctor proceeds to explain the steps taken after a patient dies]*

Jenny : *Adakah makcik akan rasa sakit?*

Doktor : *Tidak, Cik Jenny, tak perlu risau. Kami akan terus menjaga Puan Tan dengan baik.*

Jenny : *Boleh saya duduk menemani dia?*

Doktor : *Boleh, boleh... Cik Jenny boleh berada di sisi dia bila-bila masa.*

Jenny : *Apa yang akan berlaku selepas dia pergi? Boleh saya bantu dengan urusan selepas itu?*

Doktor : *Boleh kalau itu yang cik mahu, cik boleh bantu jururawat. [Doktor menerangkan langkah-langkah yang diambil selepas pesakit meninggal dunia]*

Verbal responses to avoid:

"Why do you want to do it?"

"Don't worry we can handle it."

"Why don't you just sit by the side and say your prayers."

"At this stage, she will not know if you are present or not."

"Jangan risau, kami boleh uruskan semuanya."

"Cik duduk ajelah di sini, biar kami uruskan semuanya."

"Dalam keadaan dia sekarang, dia tak menyedari pun kehadiran cik."

Case Study 11: Dying at Home

Mr Ranjit Singh, an 80-year-old man, had enjoyed good health until he suffered a massive stroke that left him hemiplegic, aphasic and dysphagic. He was ventilated in the ICU and subsequently extubated. His family was clear that re-intubation, tracheostomy and other intensive therapy would not have been what Mr Ranjit wanted should he deteriorate again. He then develops hospital-acquired pneumonia and becomes increasingly short of breath. They approached the doctor because they are concerned that their father is suffering now and that his final wish to die at home would remain unfulfilled.

Task: Address the family's concerns and support the decision to bring the father home

Specific challenges in this scenario:

The family wants to honour Mr Ranjit's wish to die at home. On the other hand, they are worried about managing his symptoms. A good death at home should be supported and facilitated. Some family members may also have to deal with their own discomforts and misgivings over this request.

Issues to Consider	Possible Reactions	Suggested Responses
<ul style="list-style-type: none">• Importance of fulfilling patients' wishes• Watching loved ones suffer• Never witnessed the dying process• Questions on time of death• Palliative care services	<ul style="list-style-type: none">• Worried• Frightened• Feeling helpless and distressed• Overwhelmed	<ul style="list-style-type: none">• Keep communication clear and honest to ensure realistic expectations• Support efforts to honour patient's wishes• Listen to family's concerns• Explain the final moments• Explain how symptoms can be managed

Possible dialogue:

- Doctor : *I was told that you wish to bring your father home.*
Family : *Yes, doctor. This is what Dad told us.*
Doctor : *I can see how important this is to your father and the family [pause] Actually, many people share the wish to die at home and we can help you.*
Family : *[long pause] [looks worried]*
Doctor : *Please tell me what is troubling you?*
Family : *Can you tell when [pause] he will pass [trails off].*
Doctor : *[gentle tone] I am unable to say when exactly he will pass on...*
Family : *[pause] We are worried because we do not know what will happen and what to do.*
Doctor : *Death is a natural process [pause] some things might occur during this time [pause] like moaning, difficulty in breathing and gasping. We can contact hospice for assistance to manage these symptoms at home.*
- Doktor : *Saya diberitahu yang waris ingin membawa Encik Ranjit pulang.*
Keluarga : *Ya, doktor.*
Doktor : *Saya sedar yang ini penting untuk ayah dan keluarga. Sebenarnya ramai yang ingin menghabiskan saat-saat akhir di rumah, kami boleh membantu sekiranya ini yang diinginkan.*
Keluarga : *[senyap] [kelihatan risau]*
Doktor : *Apa yang cik sekeluarga risaukan?*
Keluarga : *Doktor, bila er ayah akan [senyap] pergi...*
Doktor : *Sebenarnya tiada siapa pun boleh agak bila kematian akan datang.*
Keluarga : *[senyap] Kami sebenarnya risau bila saat itu datang...*
Doktor : *Ya, memang ramai yang bimbang [senyap]. Sebenarnya kematian adalah proses semulajadi. Di saat kematian seseorang mungkin akan mengerang dan mengalami kesukaran bernafas. Kami boleh hubungi pusat hospis untuk bantu cik dengan perkara-perkara sebegini di rumah nanti.*

Verbal responses to avoid:

- "He is unconscious and wouldn't feel anything."*
"Who knows when he would die."
"It is more convenient to die in hospital because..."
"Why do you want to take him home?"
- "Dia tak sedarkan diri dan tidak akan rasa apa-apa pun."*
"Kenapa nak bawa ayah cik balik?"
"Lebih senang kalau dia tinggal sahaja di hospital..."

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LIST OF ABBREVIATIONS

1	EEG	Electroencephalography
2	GCS	Glasgow Coma Scale
3	CPR	Cardiopulmonary Resuscitation
4	ICU	Intensive Care Unit
5	BP	Blood Pressure
6	IPC	Interpersonal Communication
7	HIE	Hypoxic Ischemic Encephalopathy
8	ED	Emergency Department
9	AKA	Above Knee Amputation
10	ESRF	End Stage Renal Failure
11	CT	Computed Tomography
12	ROSC	Return of Spontaneous Circulation
13	SN	Staff Nurse

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