

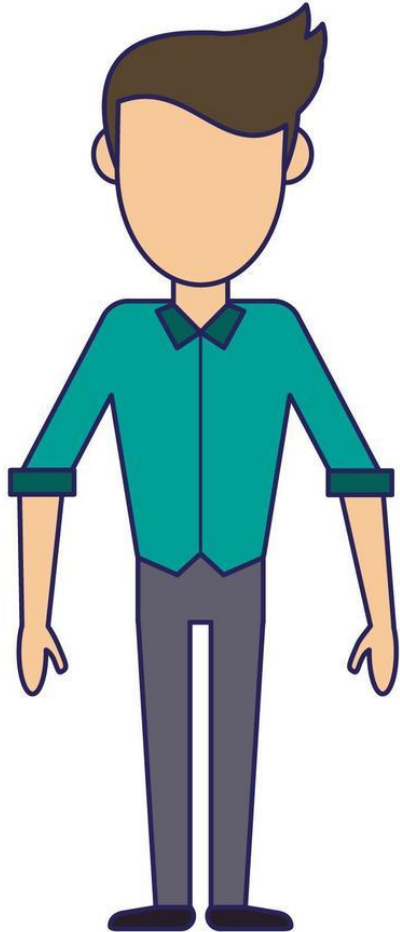


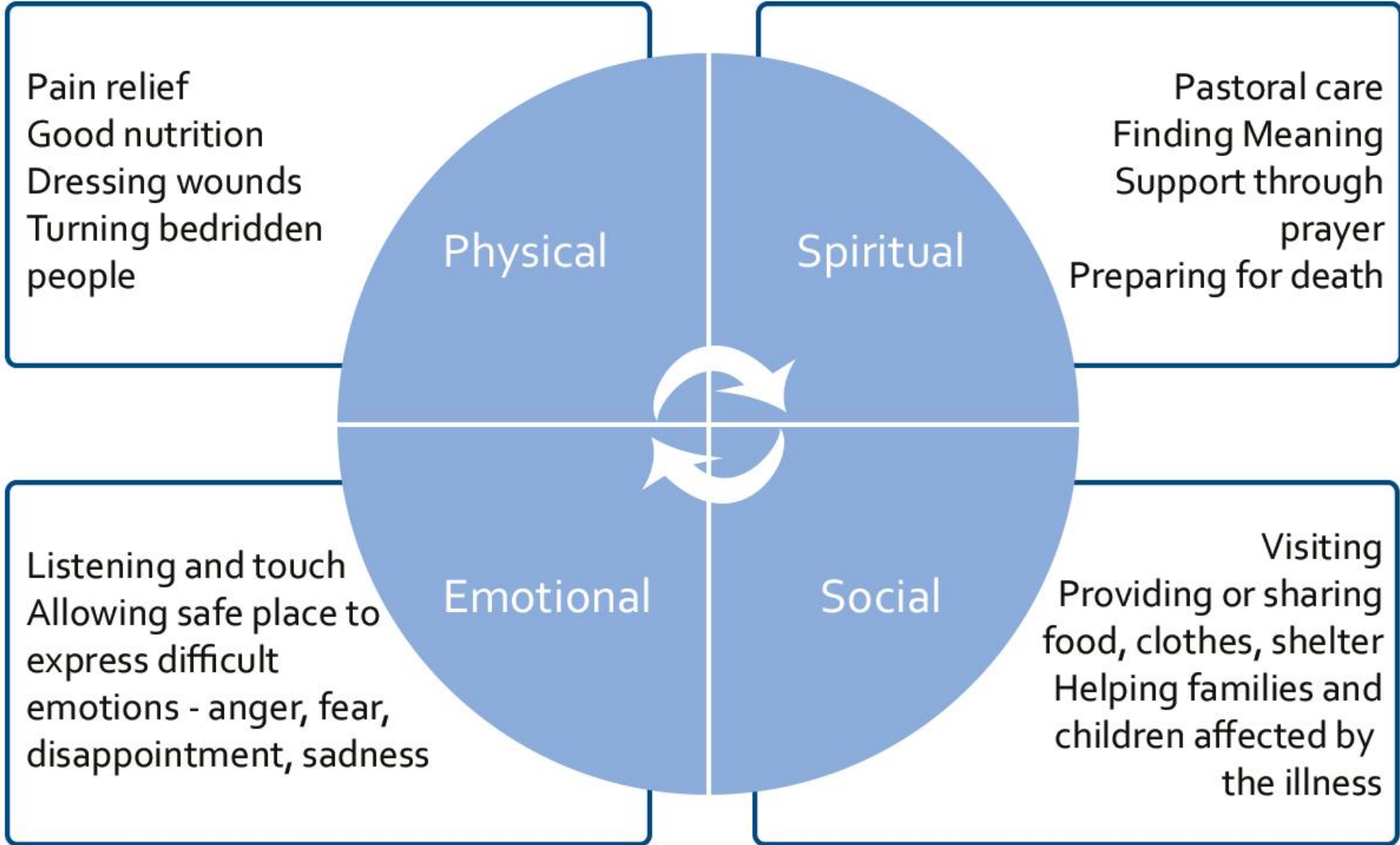
Holistic Care for Children with Cancer

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What is holistic?



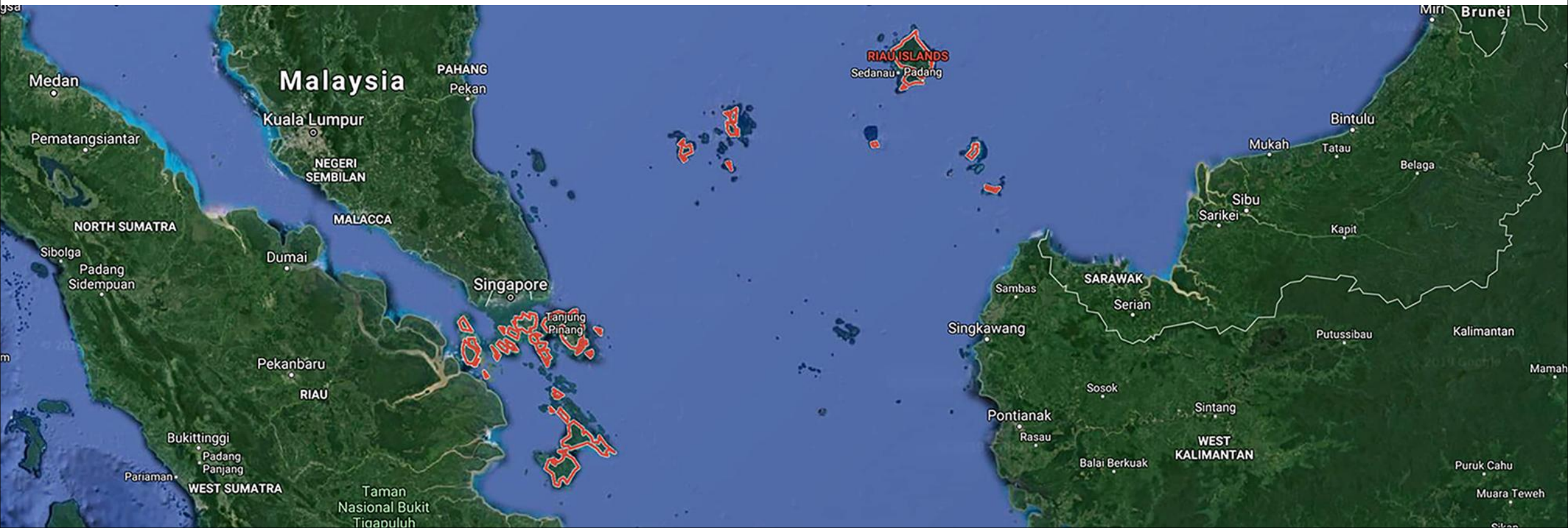


- Palliative care for children is the active total care of the child's **body, mind, and spirit** and also involves giving support to the family.
- It begins when illness is diagnosed and continues regardless of whether a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's **physical, psychologic, and social** distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centers, and even in children's homes.

and...

this is actually Pediatric Palliative Care all about

This is MY
story





Let's Start the
Journey

February 2024

M	T	W	T	F	S	S
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28	29			

Tuesday 20th Feb 2024

A patient referred to me...



- AF, girl, 2 year 6 month old.
- **Symptoms:**
 - Fever and the gum bleeds for 1 week before the mother took her to the hospital in Anambas Island. Mother also noticed that her daughter also looked pale 1 day before she took her to the hospital.
- **Physical Examination:**
 - She looked weak, body temperature $> 38^{\circ}\text{C}$, conjunctiva was pale, gum bleeds, and petechiae all over her body.

A patient...

- **Laboratory Examination:**

- Hb : 2,8 g/dl
- WBC : 53.2000 /ul
- Platelets : 12.000/ul

- **Working Diagnosis:**

- Suspect Leukemia with
Bi-cytopenia and Leukocytosis



WHAT'S NEXT?



HOLISTIC



Physical

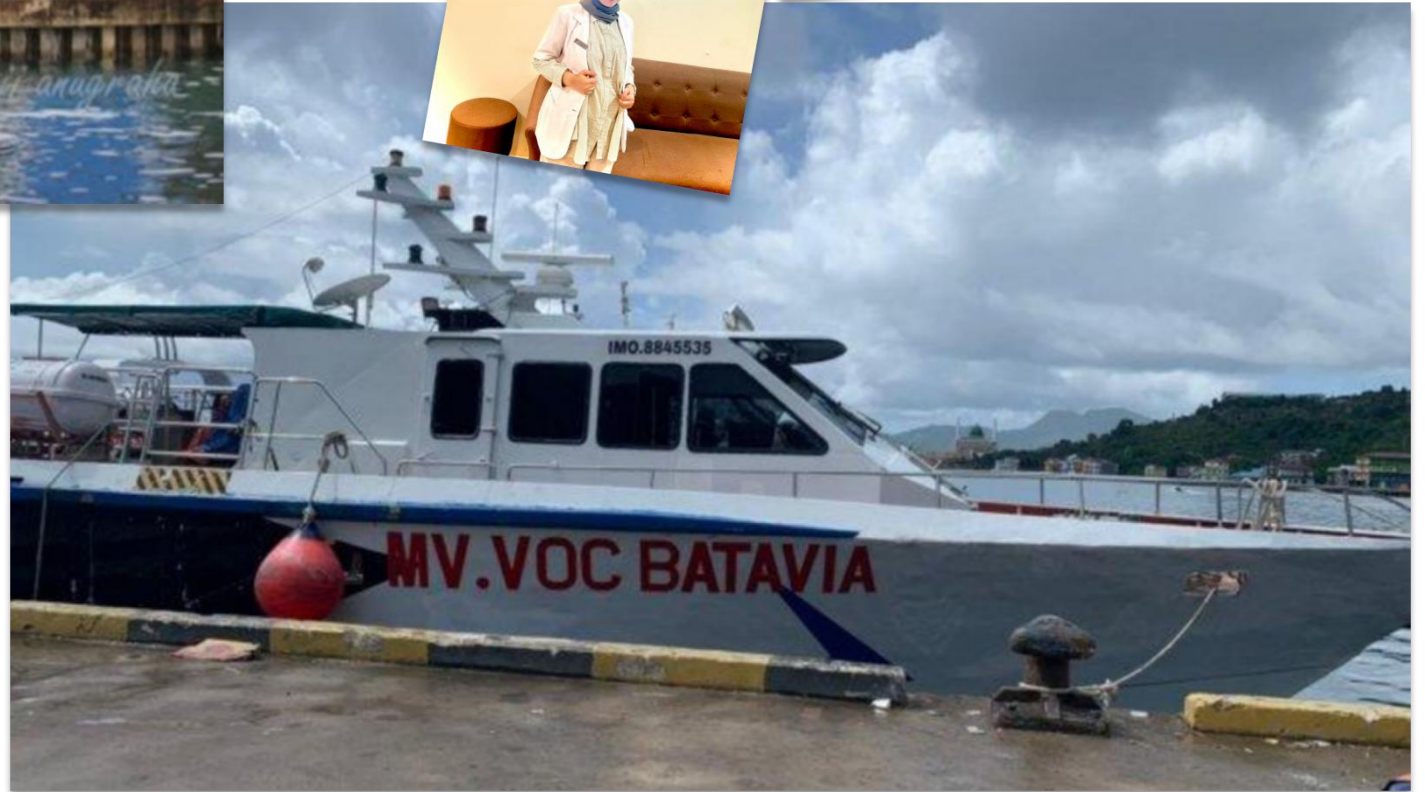
Their plan

- Antipyretic & Antibiotic.
- Oxygen.
- Transfusion (PRC & Platelet).
- Hydration.



Reality

- They cannot performed transfusion.
- **So they decide to refer this patient to Batam Island by boat that takes around 8 hours. The schedule for the boat is only on Wednesday and Sunday.**

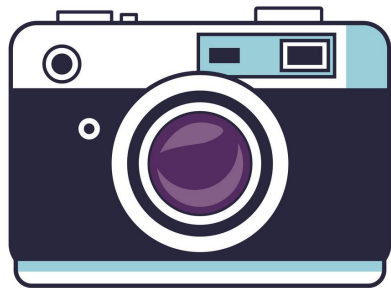


START

Psychological

Questions that came up in my mind

- How is the feeling of the mother in this kind of situation?



Reality

- Mother is a single parent. She's very afraid and panic because she had to take care her little girl by her self.
- **Mother and her girl accompanied by 1 doctor and 1 nurse to go to Batam Island.**



Psychological

Questions that came up in my mind

- Is the girl going to make it to Batam Island?



Reality

- The doctor in Anambas Island said to the girl's mother: **"At least we do something for your girl. She will make it or not, we leave it to God. But yes, she has the possibility to die on the way to Batam Island. She can passed away because her heart will stop suddenly or because of bleeding"**.

Social

Question that came up concerning this aspect

- Where are they going to stay in Batam Island? Impossible to go from Anambas Island to Batam Island, back and forth.



490.000 for 1 trip / person
by boat - 8 hours or
2.000.000 for 1 trip /person
by plane - 1 hour

Reality

- They have family in Batam Island and they will stay there during the chemotherapy.
- For medication, they use the government insurance that cover all of the expenses.
- This little girl has a twin sister back home in Anambas Island live with her auntie.

Spiritual

What about it?

- The girl's family is a Moslem family.



DO YOUR
BEST
AND LET
GOD
DO THE
REST

Reality

- I ask the doctors and nurses that take care of this girl to remind the family to pray and we can invite the ustad to visit her and her mother to give them support.

What happened when they reach Batam Island?

- They departed at 07.00 and arrived around 16.00 because of the bad weather and go straight to Awal Bros Hospital in Batam Island.
- I asked my colleague to performed complete blood count and ask the pathologist to see whether the morphology of the leucocyte is more likely to ALL or AML. I do this because I cannot do the bone marrow aspiration right away.
- As the result came out and its ALL, so I asked my colleague to start the chemotherapy right away.





*don't think that Pediatric
Palliative Care only take care the
dying child...*

BUT...



Problems:

Pain, Cachexia, Big mass,
Absence from school,
Loss contact with friends,
No activities,
Parent so protective,
Less information,
Parent not willing to involved
patient in decision making.



***Osteosarcoma
spread to the lung***

Symptoms:

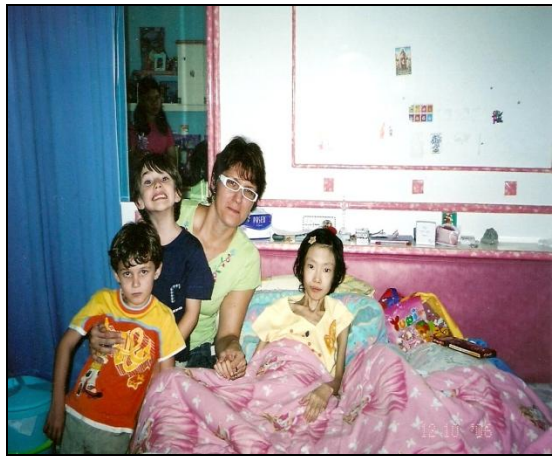
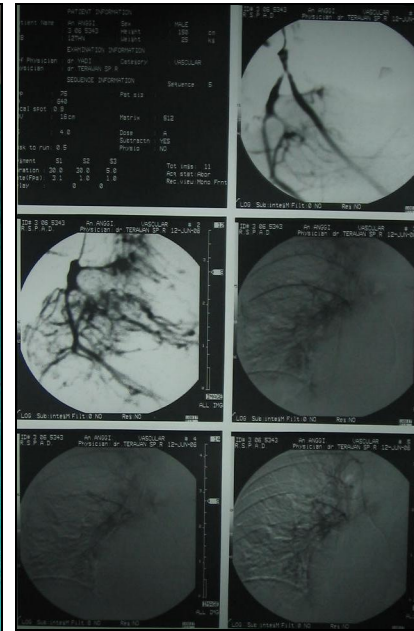
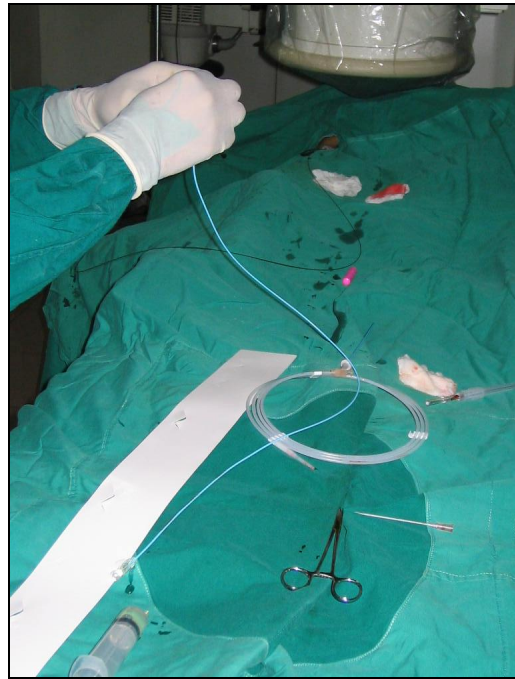
Anger, Often cry, Withdraw from her friends,
Focus on her self, Difficult to sleep

Is Anggi suffering? Yes

Cause of the suffering:

Pain, Unfulfilled wishes

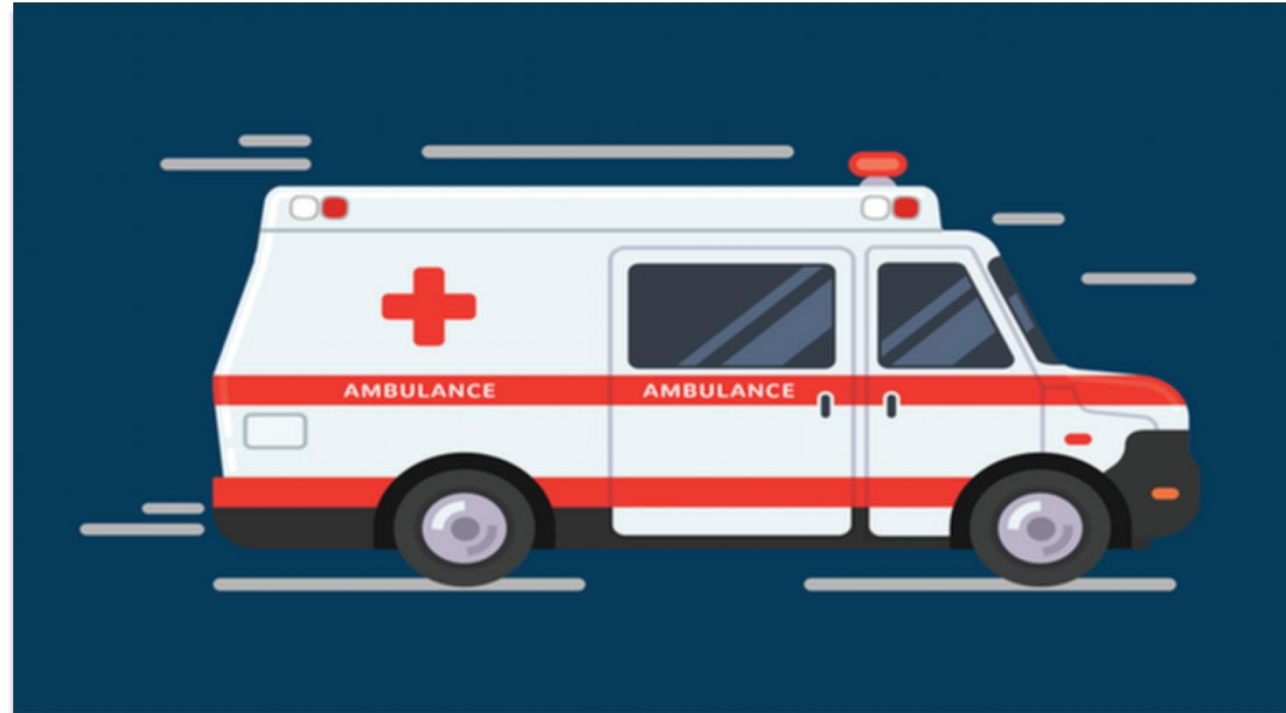
Anggi, girl, 12 year old



Approach:
Pain Management:
intra-arterial chemotherapy,
Give her a space,
Give the information that
she need, Involved her in
decision making, Create a
nuance of a place that she
wants to be in her room.

Anggi, girl, 12 year old

Shall we take her to the hospital?



Ask these questions...

- ❑ Is the child's condition reversible?
- ❑ By taking the child to a hospital, will it prolonged his or her life?
- ❑ Is the child will get a good care in the hospital?
- ❑ What is actually the child want?
- ❑ What is actually the family want?

A child's suffering begins with excessive parents...

Anggi's father



not only **act** holistically

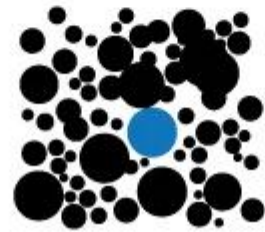
but also **think** holistically

REMEMBER

- Pediatric Palliative Care is not a matter that your patient is going to die or not. The point is that we take good care of our patient the best that we can.
- Pediatric Palliative Care is when you see a suffering child not only from his or her physical but also psychological, social, and spiritual aspects (Holistic Care).
- Pediatric Palliative Care is not about right or wrong. There is no such thing as right or wrong in Pediatric Palliative Care.
- Pediatric Palliative Care is when you treat 10 children with individual approach for each child because Pediatric Palliative care is an art.

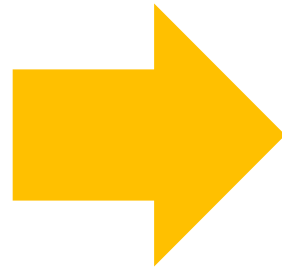


what happened





**When she arrived on the
20th of February 2024**



CHEMOTHERAPY



On the 29th of February 2024



MANY THANKS

RSUD Terempa

- **dr. Kamila Arifa, Sp.A**
(Paediatrician)
- **dr. Kurniawati**
(General Practitioner)
- **Masni, S. Kep**
(Nurse)

Anggi's family

RS Awal Bros Batam

- Board of Director
- **dr. Dewi Metta Sidarta, Sp.A,**
M.Kes (Paediatrician)
- Nurses and staffs in PICU
- Nurses and staffs in
Chemotherapy Room



My Story.

what's your story?

Thank You