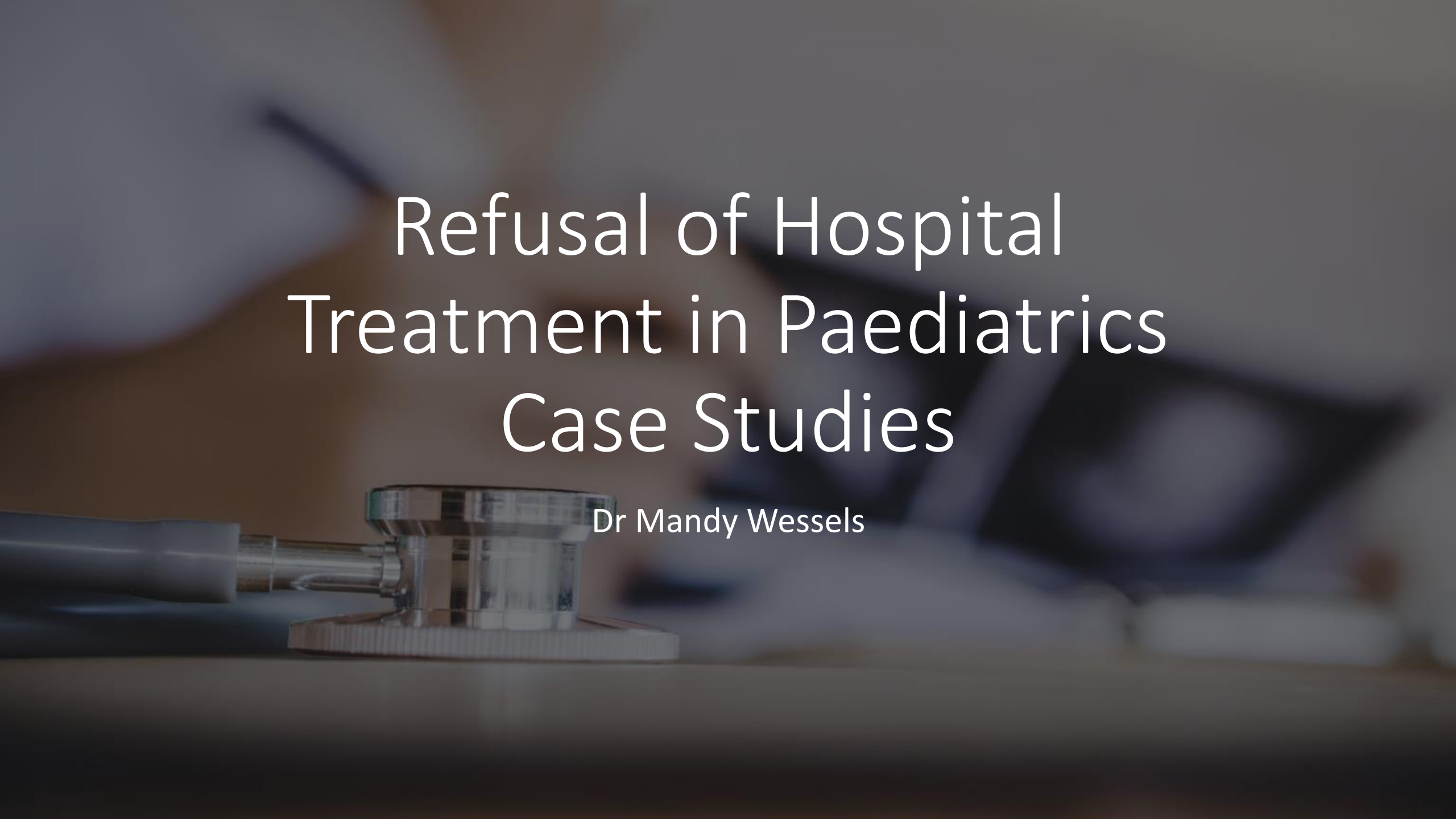

Refusal of Hospital Treatment in Paediatrics Case Studies

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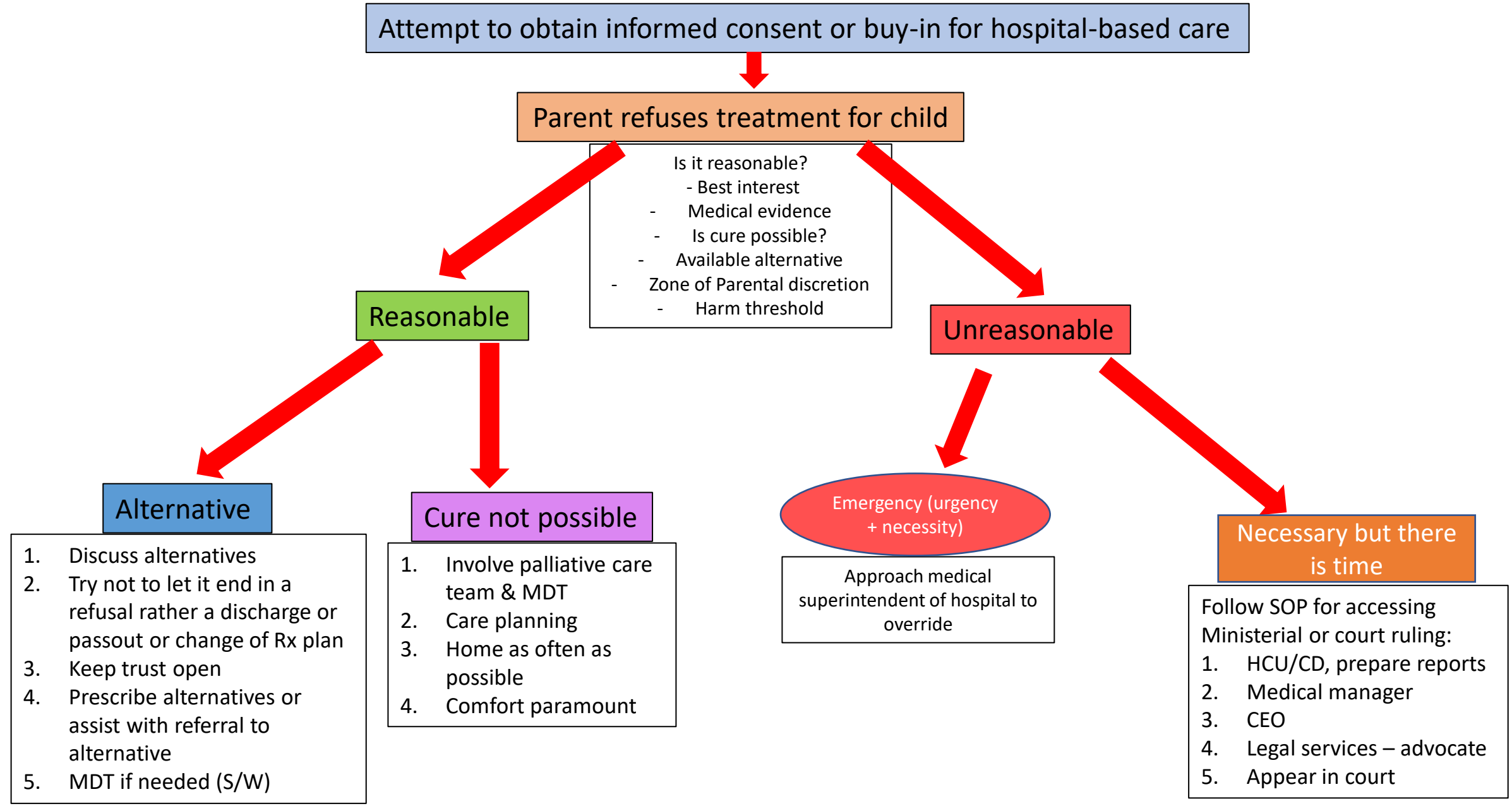
Attempt to obtain informed consent or buy-in for hospital-based care
Parent refuses treatment for child
Is it reasonable?
- Best interest
- Medical evidence
- Is cure possible?
- Available alternative
- Zone of Parental discretion
- Harm threshold
Reasonable
Unreasonable
Alternative
1. Discuss alternatives
2. Try not to let it end in a refusal rather a discharge or passout or change of Rx plan
3. Keep trust open
4. Prescribe alternatives or assist with referral to alternative
5. MDT if needed (S/W)
Cure not possible
1. Involve palliative care team & MDT
2. Care planning
3. Home as often as possible
4. Comfort paramount
Emergency (urgency + necessity)
Approach medical superintendent of hospital to override
Necessary but there is time
Follow SOP for accessing Ministerial or court ruling:
1. HCU/CD, prepare reports
2. Medical manager
3. CEO
4. Legal services – advocate
5. Appear in court

Case 1

- A 10-week-old baby presents to your paediatric service with irritability, fever and a bulging fontanelle
- You wish to do a full work-up to elicit the source of sepsis, including a lumbar puncture, as meningitis is top of your differential diagnosis
- While obtaining informed consent, the mother says she will not consent to a lumbar puncture but is happy for you to take bloods, urine and insert an ivi line for antibiotics
- As you explore her reasoning, you find that she had a relative who demised shortly after a lumbar puncture, leading to fear of the procedure itself. You also find that she is from a traditional background and doesn't feel comfortable to consent without consulting the father of the child and the elders at home

Case 1 Discussion

- **This is a common scenario – initial refusal of a procedure**
- Reasonable? It depends
  - This becomes more difficult when trying to tease out TB meningitis and imaging may take long to arrange
- Very often, the family come to agree after
  - fears are addressed;
  - blood results shared
  - duration of empiric antibiotics are discussed
- The other parent may consent and you only require one parent to consent, though unity in the decision is always ideal

Case 1 Guiding Principles & Reminders

It may be safe to allow some flexibility within the “zone of parental discretion” but to be clear in your own mind and the family’s about where the harm threshold lies

When the harm threshold is reached and best interests are no longer honoured, attempt to get consent again must follow and then escalation if still refused

Important here to allow space for revisitation, work hard not to project frustrations onto the family and impair the relationship and try not to let the refusal impair the relationship.

Case 2

- TM is a 14-month-old baby with Trisomy 21. He has a massive AVSD and was never operated on due to late diagnosis and established Pulmonary Hypertension by the time of planned surgery.
- TM is well-known to your team, having been admitted often for LRTI and oxygen therapy as well as regular collection of anti-failure medication.
- On this admission, TM has been oxygen-dependent for 2 weeks. Despite optimising anti-failure meds and treating the pneumonia with antibiotics, TM has oxygen Saturations that are between 70 and 80%
- The mother approaches you, requesting to sign baby TM out of hospital and take him home.

Case 2 Discussion

- ***Also common, possibly easier to navigate***

- When the medical team and caregivers have reached an understanding and acceptance that cure is not possible, it is reasonable for the family to request end-of-life care at home
  - The difficulty lies in the cases where the deterioration is slow or when oxygen-dependent and it is difficult to get the child home
  - Also challenging that we and the family may not always align in terms of timing
  - Often the family takes a child home for end-of-life care and then finds they are not coping, important to not label this as refusal of care and have an open-door policy for return

Case 2 Guiding Principles

- Allowing a child home for end-of-life care should not be seen as refusal of prolonged admission
- Parents should not have to “sign the child out”, rather discharged
- Good, signed counselling and an advanced care plan should be in place, detailing
  - that the family has understood that cure is not possible
  - what death will look like/terminal event
  - that they have the capacity to cope at home is essential
- The family should always know they are welcome back if symptoms are too distressing

Case 3

- A 2-year-old boy presents with a surgical abdomen
- The surgeons assess the child and feel he needs an urgent laparotomy, suspecting a ruptured appendix and pus in the abdomen
- The caregiver is 17-years old and requires assistance from her parents to consent to the surgery
- The grandparents refuse consent, saying they want the child to go to a traditional healer, that the cause is likely because the ancestors are unhappy that the Mother had a baby so young

Case 3 - Discussion

- When a teen mum is under 18 years, she does require assistance from the grandparent on ***form 35*** to agree to surgery on her own child (the teen parent may consent, with assent from the grandparent)
- The grandparents are unreasonably withholding consent for cultural beliefs, which you believe are not in the best interests and against medical evidence
- There is no time here to approach the court
- The medical superintendent will need to be approached because it is an emergency

Case 3 Guiding Principles

EMERGENCY = URGENCY + NECESSITY

Medical Superintendent may provide the assent in this case

May also provide full consent in a case where the primary caregiver unreasonably refuses or is unavailable and there is urgency plus necessity

Consent from the Medical Superintendent is not appropriate in cases where there is time to approach the Minister of Social Development or Court and is not appropriate where there are acceptable alternatives

Case 4

- A 6-week-old baby, ex-prem with corrected GA 1 week, is requiring surgery for an inguinal hernia, which is not reducible but not yet incarcerated
- The Haemoglobin done pre-op is 5.8
- The family have consented to the surgery but have stated that they are Jehovah's Witnesses and will not consent to blood transfusion.
- The surgeons and anaesthetists do not feel safe to proceed without blood

Case 4 Discussion

- The surgery is necessary though not immediately so
- The blood transfusion is necessary to optimize the baby for surgery
- Jehovah's witness foundation always take our calls and ask us to try alternatives first, aware that the law will eventually allow transfusion. This provides comfort to the family
- The suggestions are to try intravenous iron and Erythropoetin. In this case we do not feel this will help, given the mechanism of the anaemia and the time to take effect
- Alternative caregivers may be contacted – often the other parent does not practice or does not feel as strongly on religious grounds
- Mother may request that such an alternate caregiver signs the consent and that she is not present during transfusion but otherwise does not obstruct
- If all the above fails – activate the SOP to access the courts

Case 4 Guiding Principles

- Consent cannot be withheld on religious grounds alone
- There is time, thus the medical superintendent is not appropriate here
- Once you realise the court needs to be approached
  - This starts with notifying those senior to you – HCU, HCD, Medical Manager, CEO and then legal services
  - Reports will be required so you should start writing these immediately so they are ready
  - Ongoing care should continue for the child and consent revisited while in the process

Questions