

Introduction:*Introduce myself.*

Give me one word that you think of when you hear the word 'Chaplain'

Pastoral & Spiritual Care – about care of the spirit; Spirituality is about what gives meaning, our values etc

I'm going to share today a bit about what I've learnt about the spirits of those families on our wards. Because this is a children's hospital I'm going to use a children's book – The Red Tree by Shaun Tan as a basis for this reflection. I invite you to use this time to reflect on what you have experienced when meeting families facing a crisis with their child's health

1. Sometimes the day begins with nothing to look forward to

For some parents this might be the day they come to hospital for a regular check up; I've met parents who've learnt that the regular outpatients appointment is quite likely to turn into an admission so they automatically pack a case to bring just in case.

Sometimes a child has been sick for a few days and someone reassures the family that this is a minor thing; that they shouldn't worry. But some instinct nags at a parent

1. and things go from bad to worse

A child can go downhill quickly, and worry increases until a family makes a trip to emergency; or that case goes upstairs with a family as a child does need to be admitted

2. Darkness overcomes you**3. illustration**

Sometimes a diagnosis is a nasty one requiring long term nasty treatment.

Sometimes a serious condition is identified a genetic condition and parents must face the fact that any future babies risk being born with the same condition

4. nobody understands**5. illustration**

Sometimes family or friends try to help by attempting to cheer up parents or by telling them that God chose them to deal with this because he knows they have the strength to cope, Or by pushing them to think only positive thoughts even though their very world appears to be shattered.

Or friends stay away in case their child might catch something – even when a condition is not contagious – or they stay away because they don't know what to say.

A parent can feel very alone even when surrounded by others

6. the world is a deaf machine**7. illustration**

Sometimes there appears to be no-one listening. I remember walking down the corridor in the NNU when a nurse spotted me and asked if I might be able to help. A newborn baby was scheduled for life saving surgery the next morning and the family was expecting their priest in that afternoon to baptize the baby. Unexpectedly a spot became available in theatre so the surgery was to be brought forward to that afternoon. The mother became distraught and declared that she would not sign the papers to allow the surgery to go ahead. I suspect the nurse asked for my help thinking that as the religious person I might be able to talk 'reason' to the mother but my understanding of the situation didn't suggest I should be attempting to talk her into anything.

- What do you think she might have needed?

The world was a deaf machine for this mother....what I did ...

8. without sense or reason*9. illustration*

We live in a rich country with fine medical resources. If we lived in a developing country our expectations would not be so high but here it can be a huge shock when a child is found to be seriously ill.

* People ask: Why has this happened? Why an innocent child? Why not me?

Is this because I have done something wrong?

* On television usually a sickness is diagnosed, treatment given and healing comes within an hour. In real life we don't have quite that expectation, but most families do expect a diagnosis fairly promptly and in the rare cases when this doesn't happen for a few days...or a few months....or not at all, then that doesn't seem to make sense.

* Or sometimes two medical teams are involved in a complex situation and each have a preferred way of progressing. This doesn't seem to make sense either.

10. sometimes you wait, and wait and wait and wait**11. and wait and wait and wait but nothing ever happens**

You might wait with your sick child all night in emergency, until a bed on the ward becomes available;

you might wait for tests, for test results – some take weeks; you might wait for surgery, doctors, discharge. You might wait months at home for a transplant donor, or you might wait months in hospital for a donor.

12. Then all your troubles come at once*13. illustration*

You might have casual work and no paid leave;

or someone might suspect that your child's injury might not be accidental so DHS is called in.

Or a grandparent suddenly confronted in this new grief, finds past losses and griefs beginning to arise in a frightening way

14. wonderful things are passing you by*15. illustration*

Some families can see whole seasons pass them by as they wait in hospital, family birthdays, an important event for another child in the family, new pregnancies of friends while their own hopes are all on hold.

16. Terrible fates are inevitable*17. Illustration*

Somehow the worst outcomes are often the ones that come to mind while waiting for a firm diagnosis

18. **sometimes you just don't know what you are supposed to do*19. illustration*

Often a mother will talk about feeling torn; about feeling the need to be in hospital with their child and about needing at the same time to be home with other children who are also suffering.

- A very sick child has an impact on each person in the family and on the whole way a family functions.
- Sometimes a family is worried about an autistic child who has become too strong and unco-operative for a parent to keep safe. The parents may be advised (off the record by someone)

to just not collect the child from their respite care facility – what a painful decision to have to make. * Sometimes a decision must be made whether or not to continue life support.

20. sometimes you just don't know who you are meant to be

21. illustration

'Am I a father or mother or am I a nurse? This is a question I hear. 'I expected my touch to be comforting but now my touch often involves participating in painful treatment for my child.'
A family in crises can oscillate between faith and despair..

22. sometimes you just don't know where you are

'Should we be here?'

I am not feeling confident to go home even though I am told that medically my child is ready for discharge.

23. illustration

24. and the day seems to end the way it began

or the days just continue on in the same way

25. but suddenly there it is right in front of you, bright and vivid, quietly waiting

26. just as you imagined it would be

A red tree

Hope comes like the red tree; often quietly, often profoundly, unlike the red tree it is often in an unexpected way

* In most cases a diagnosis is made, a treatment plan is developed, a child is discharged

* Sometimes hope reemerges as families explore their grief and pain and find grace in what they are able to enjoy. Learning to value each day as it arrives rather than focusing on the long term and what might or might not be.

* Hope changes during the process of hospitalization and often the transformation that takes place is not 'just as the person imagined it would be' but it can be a good place.

Many times I have heard a parent say that they will never take things for granted again, that life has become more precious and that priorities change enormously. No longer is a clean house the most important aspect of life, nor career progression, nor accumulating things.

It can be hard learning to just be with a family. We can feel drawn into wanting to do more to help. How do you overcome this desire to break the boundaries by becoming over involved? Referral through the ward clerk is often a good way to go.

It is a privilege to journey with families. Both Chaplains and volunteers are in the position of not having a role in fixing a person or a situation but to offer a valuable service of listening and companionship to a child or a family.

I wish you well in the important work you do here. I also invite you to visit Murrik Biik our Prayer and Meditation space if you haven't already done so. It is a special, quiet space to sit especially if you have had a tough day. We Chaplains are unique in that we are here for patients and families, but we are also here for staff and volunteers. If you would like to talk with a Chaplain you are welcome to make contact – you might need to leave a message and contact details if we are not in the office – but we would be happy to get back to you.