



IN MEMORY OF DR MEHNAAZ AKBAR ALLY

A doctor who truly cared for children,
their families and their caregivers

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PAEDIATRIC PALLIATIVE CARE

A PARENT'S PERSPECTIVE

MELISSA WILLIAMS-PLATT

Sam's Mum, Healthcare Consultant & Integral Coach



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6 months, one year ... now 9 years without you

POEM FOR SAM

IT IS just one of those things....

The spoken words leave your mouth
and the unsaid scorches your heart -
because what you are really saying is:

IT IS The One Thing -

... that shatters your soul
... that makes you want to scream
... that tears you apart
... that no parent should ever have
to endure
... that you will never understand
... that you will always question
... that shakes your faith to its very core
... that destroys your equilibrium
... that keeps you up at night

... that drains your tears
... that strips you bare
... that saps your husband before
your eyes
... that takes the perfect 3 of you to 2
... that fills the eyes of all those you
love with reflected pain
... that gnaws away at you each
second of every day
... that changes a family forever....

The Death of your precious
child is that -
That ONE Very Thing that should not,
ever be
One of those things....

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*Melissa
Sam's Mom*

Sam's Key Life Lessons - Transforming curing into healing

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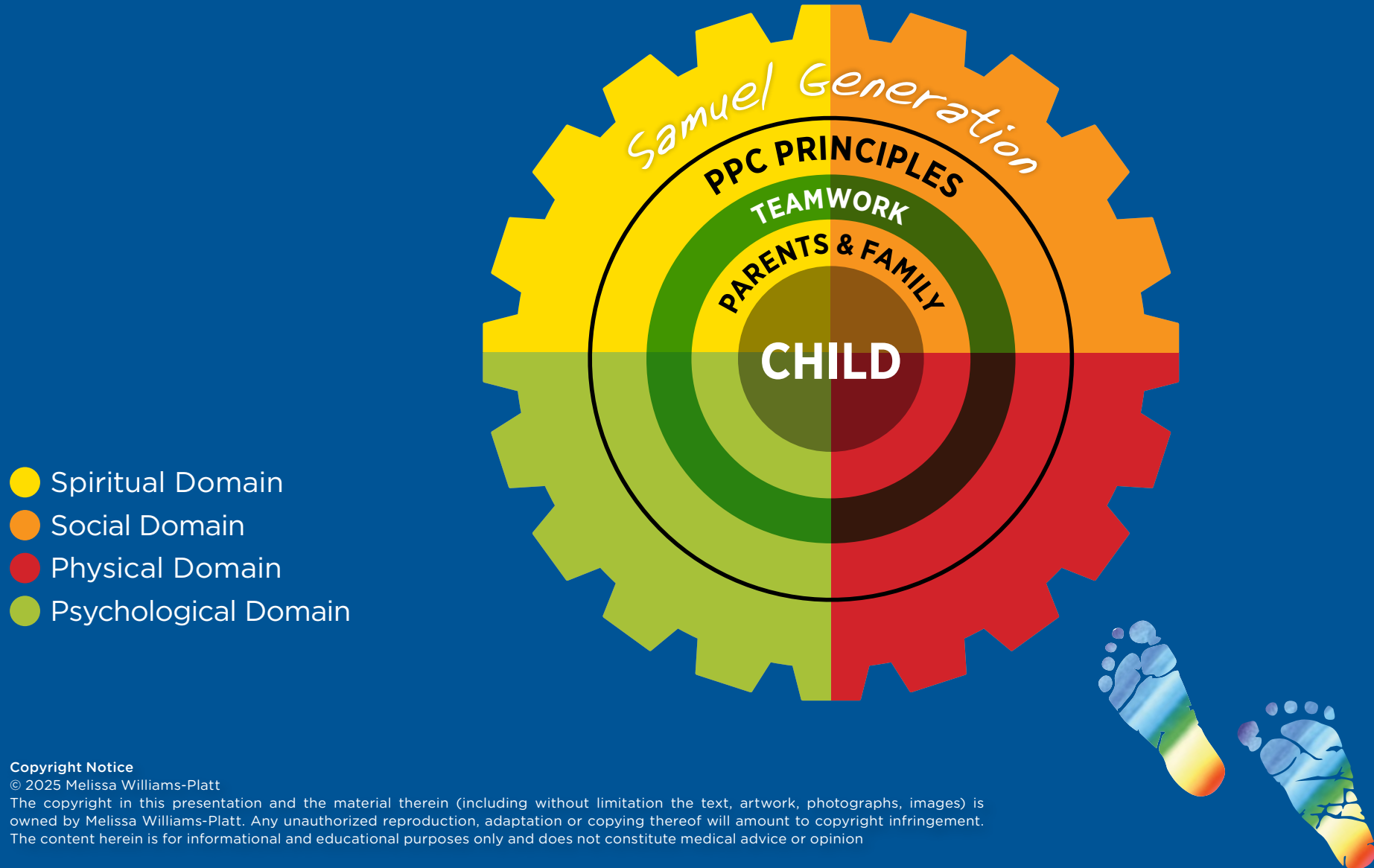
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The Samuel Generation

Lessons from Sam ...

The Samuel Generation Model -
An Integrated Healthcare Approach



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Key lessons from Sam:



HOLISTIC TREATMENT

Treat the whole child not just the symptoms. Sam says: “I am Sam. I am not just the sum total of my symptoms. I AM SAM!”



WE ARE HUMAN

A child is a person, a human first and foremost and so are you. Always offer hope and always respect the child and family’s dignity.



FAMILY SUPPORT (NOT DIFFICULT JUST SCARED HAVING LANDED ABRUPTLY ON MARS)

Chronic illness impacts on the whole family. How are they coping? Are they supported? Are they empowered? Have you allowed their voice to be heard?

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EXCELLENCE OF CARE

As a doctor and a health professional, work as a team. An integrated multi-disciplinary team caring for a patient holistically = excellence of care.



IT IS HUMAN TO ERR

Health professionals can be wrong and can say that they do not know. This is not failure. This is being human and we applaud you. It is human to err.



SAY YOU'RE SORRY

IT IS OKAY to say you are sorry. In this way you will save families from much guilt, grief and heartbreak. In fact saying you are sorry may even be the simple answer to many medical-legal woes.



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RELAY OF EXCELLENCE

Subscribe to a “Relay of Excellence”.
Pass on the baton when you don’t know.
There are many other specialists who
can and will help.



SECOND OPINIONS

Families are entitled to a second opinion.
Do not take it personally.



IT’S NOT ABOUT YOU

ALWAYS do what is best for the child and family.
Empathetic healthcare and egos do not mix well, so
rather try and leave egos out of healthcare all together.

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QUESTIONS

Questions from families are just questions. They are not being “difficult”. They do not, not trust you. They are simply scared and seeking answers. Mutual respect and good communication is key. “Never stop listening and learning” says Sam...



LIFE BEYOND RESTRICTIONS

Sam never went outside other than when being transferred between hospitals. Children must be allowed to play, to breathe fresh air to LIVE despite their restrictions. ICU is not a home for children. Seek ways to let a child be a child!



TRANSITION HOME

Get a child home as soon as possible. We have compiled a Parent’s Survival Guide for ICU to ensure that parents are better equipped and supported when facing the scary roller coaster of months in hospital and the transition home.

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SUPPORT THROUGHOUT A LIFETIME

When a complex illness is recognised, (since diagnosis can take months or even years with some children remaining undiagnosed), bring in a holistic team approach, as provided by a Palliative Care Team. Paediatric Palliative Care (PPC) is about supporting quality of life throughout a child's lifetime, which can be many years. Let's bust the myth that PPC is just for end of life care, since this could not be further from the truth. PPC is about supporting paediatric patients to live WELL and so must happen on recognition of a chronic illness and not left until a child is critical and dying.



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BE KIND

And above all says Sam:
“BE KIND. Your words are written on our hearts forever.”

And words from my Mum:

“You get a do-over. Sadly, as parents, we never will.”



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Sam's Footprints...

Our Commitment to our Son is to ensure his bravery and loving spirit lives on through others and that his life lessons save other lives...

A trail of footprints touching hearts and lives, bringing change and hope wherever they go...



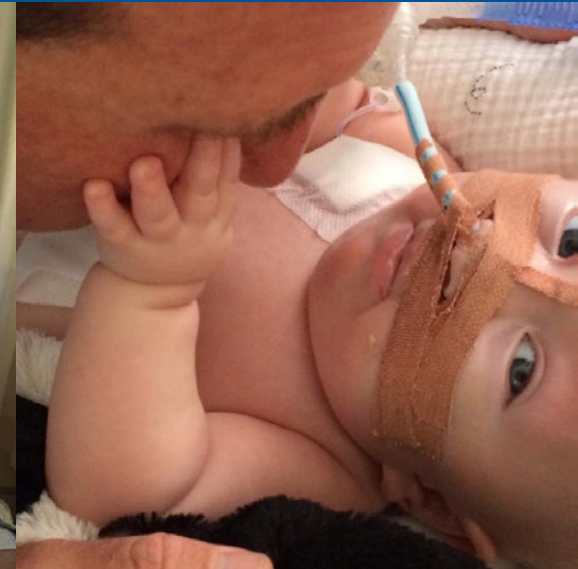
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THANK YOU



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 **Footprints
4 Sam**