

★ Was  
✧ This ✧  
in the  
PLAN?  
ℳ

Stephanie  
Nimmo

# Once upon a time I was just another ordinary person.....

- I met my husband at uni, we moved to London, bought a house, we had bright successful careers....
- 3 beautiful children
- And in 2004 I found out I was pregnant with a much wanted fourth child

\* Was  
\* This \*  
in the  
PLAN?  
e

# But things didn't go quite to plan

Polyhydramnios  
Obstetric Cholestasis  
Anaemia

Reduced movements

Large head/short femur but  
all within normal limits

Premature delivery by C-  
section



Failure to thrive

Week cry

Back arching

“we were waiting for the  
crisis”

Was  
This  
in the  
Plan?  
e

Nothing in my previous life ever prepared  
me for the huge cultural change that hit me  
the day my daughter was born.....

\*Was  
\*This\*  
in the  
PLAN?  
e

# How did I feel?

Disempowered. I was a highly skilled senior marketing professional but I felt like I had been parachuted into an alien world.

I had to learn a new language and get to grips with all the jargon...and quickly, this was about my child's life – pressure to get it right

I felt like I was in a goldfish bowl

I was tired, stressed, full of post-natal hormones

I was scared and worried....mourning the loss of the child I thought I would have, getting to know this new child.....

\*Was  
\*This\*  
in the  
PLAN?  
e

# We had an advantage

We were educated and articulate, with professional backgrounds and english as a first language

Daisy was a our fourth child, we were experienced parents

In some ways we had time to adjust to this life

Yet despite that we still had feelings of disempowerment, not being included, not having a seat at the table

\*Was  
\*This\*  
in the  
PLAN?  
e

# Tipping Points

- “I don’t know but I’m going to work with you to find out”
- Calling me by my name
- Recognising that we needed support – hospice referral

Was  
This  
in the  
Plan?  
e

# Tipping Points

- First experience with genetics
- My experience not being acknowledged by nurses
- Feeling excluded from big decisions and conversations

\* Was  
\* This \*  
in the  
PLAN?  
e



# Taking off the seatbelt

- We felt like we were in a speeding car, bracing ourselves for an inevitable crash. All the while we were bracing ourselves, knowing that Daisy would die before adulthood we were missing out on the scenery flying by, enjoying our time with our family, so we decided to remove our proverbial seatbelts and just try and enjoy the ride.....
- The little things are the big things.....

Was  
This  
in the  
PLAN?  
e



# The slow and long deterioration

- Pan-enteric colitis: TPN dependency
- Colectomy/Ileostomy
- Neuropathic bladder/mitrofanoff stoma
- Wheelchair dependency (having previously been able to walk)
- Drug resistant, multi-focal epilepsy
- Behavioural challenges
- Loss of skills – was it the drug treatment or her condition?
- Multiple surgeries/procedures/poly-pharmacy

# Quality of Life

- What constitutes a good quality of life?
- For Daisy it was to be able to do the things she wanted; go to school, be with her siblings, play with her dog
- Everything I did was to ensure that she minimised time in hospital and maximised time at home

Was  
This  
in the  
PLAN?  
e



# Palliative Care

- Focused on quality of life – what did that mean for Daisy?
- Managed symptoms
- Advocated for support
- Helped us think about end of life planning – difficult conversations
- Meant that we had some sort of control
- Meant we were not alone

Was  
This  
in the  
PLAN?  
e

We wanted professionals  
to see Daisy as a little girl,  
not a list of symptoms or  
a patient.

This was our life 24/7. We  
never switched off, we never  
got a break from worrying or  
thinking about Daisy



\*Was  
\*This\*  
in the  
PLAN?  
eg

We needed to feel empowered, valued and involved – collaboration

We needed to feel that medical professionals had an understanding of what it felt like for us

We valued openness and honesty

The internet and social media was my best friend and my greatest enemy – to advocate I had to be the expert

\*Was  
\*This\*  
in the  
PLAN?  
e

# End of life planning – our experience

- Early referral to hospice support
- Early referral to palliative care services, framed as symptom management
- Advanced directive
- Difficult conversations and decisions

\* Was  
\* This \*  
in the  
PLAN?  
e



# End of life planning



Became even more important when it was clear that I was going to be on my own.



Was  
This  
in the  
Plan?  
e

# Daisy's last year

The window was closing

She no longer had the emotional strength to fight

But she was clearly not at end of life....moral dilemma

As always, Daisy called the shots and decided that it was her time



# Daisy Rose Nimmo



**22/12/04 – 31/01/17**

\*Was  
This  
in the  
PLAN?  
el

# After Daisy Died

- We were offered the opportunity to spend time with her alone
- We brought her home for the night
- We took her to the hospice and prepared for her funeral

\* Was  
\* This \*  
in the  
PLAN?  
e

# What worked for us:

- Open conversations with medical professionals
- Feeling part of a collaborative team – we had a seat at the table
- Friends who understood us – support group
- We needed to know what was possible - drugs, treatment options
- We accepted what was not possible - transplant
- Knowing that there were people fighting our corner
- An understanding of the ripples and the emotional toll
- Our 24/7 life

Was  
This  
in the  
PLAN?  
eg

# What can we do?

- Communication between parents and professionals – collaboration, working together
- Ensuring parents feel part of the team
- Early referral to palliative care but ensuring the parents understand it's not about giving up
- Opening up difficult conversations about death and dying
- Supporting the parent's mental well being

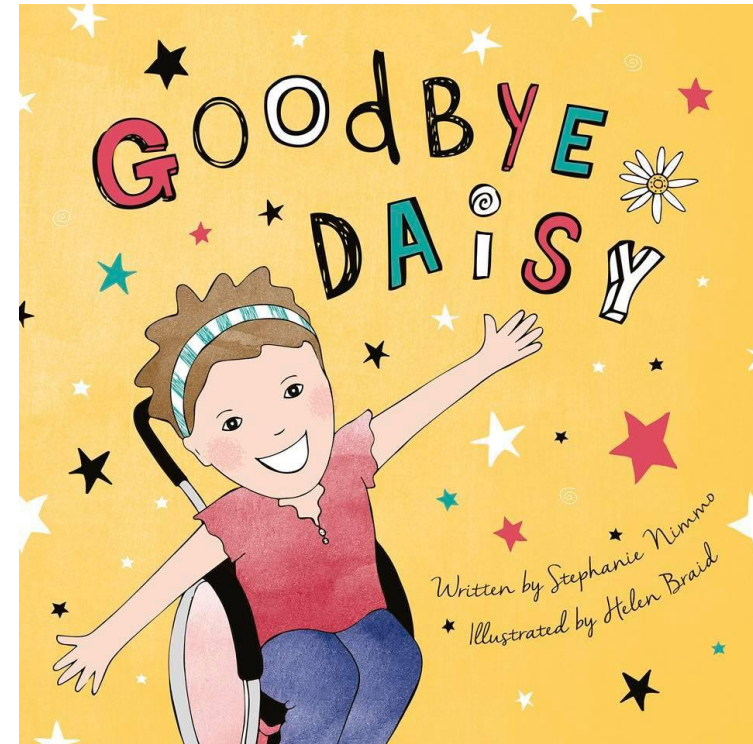
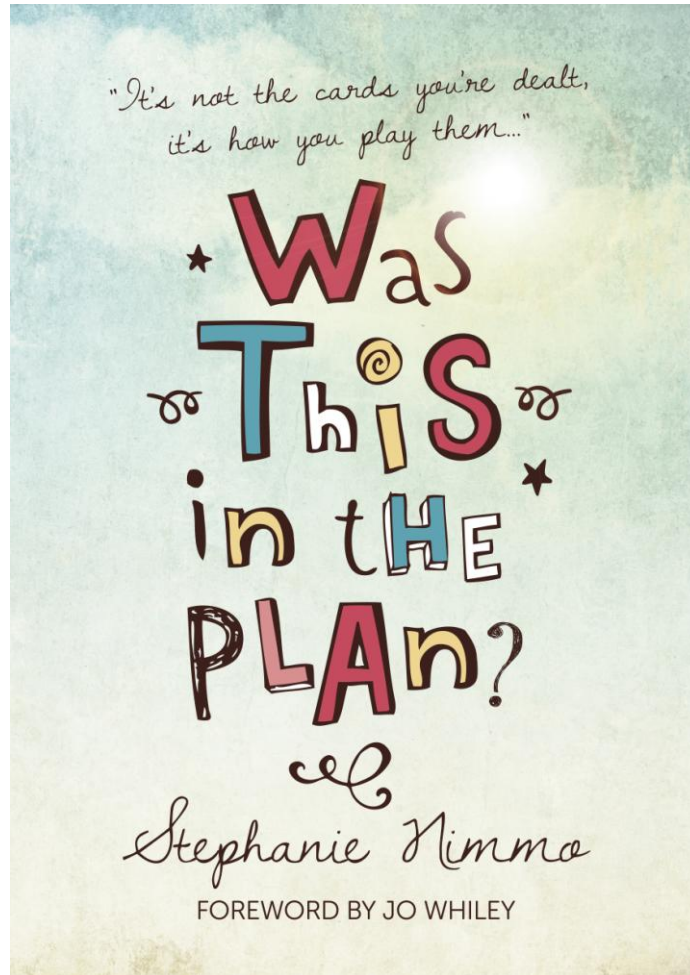
# If you can just do one thing?

Take off the metaphorical white coat and think about how it would feel if it was you.....

Be honest “I don’t know”

“Don’t call me mum”





Was  
This  
in the  
Plan?  
Stephanie Nimmo



# Stephanie Nimmo

Twitter: @stephnimmo

Facebook: [www.facebook.com/wasthisintheplan](http://www.facebook.com/wasthisintheplan)

Blog: [www.wasthisintheplan.com](http://www.wasthisintheplan.com)



\* Was  
\* This \*  
in the  
PLAN?  
e