

THE ROAD NOT CHOSEN

NG KUI CHOO
UNIVERSITI TEKNOLOGI MARA
CAWANGAN SARAWAK

NECIC 2012 Sibul Malaysia 1

The Road Not Chosen

In the year 2008, a mother in the UK was imprisoned for murdering her daughter.

Joanne Hill

Joanne Hill was sentenced to a minimum of 15 years in jail for drowning her four-year-old daughter, Naomi, in the bath. Naomi suffered from cerebral palsy.

Hill, who had previously suffered puerperal depression, the most severe form of postnatal depression, denied murder on the grounds that she was suffering from a severe mental illness. But the jury took just 90 minutes to convict her of murder. Her husband later described her as evil.

But Hill's is not an isolated case. While most parents love their disabled children unconditionally, they are also worn out by endless battles for the services they are entitled to.

NECIC 2012 Sibul Malaysia 2

The Road Not Chosen

Asher Nardone, mother to Callum, a severely disabled boy.

"It's the little things that can tip you over the edge", says Asher Nardone, mother of two boys, one of whom is disabled.

"On Sunday, Callum was sick on his bed, so I showered him and washed his sheets. Then he pooped in his bed, so I washed his clothes and sheets again. Then he spilt milk over his bed, so the sheets had to be changed again, and after that he spilt baby oil over the bed. By lunchtime, I'd had to do four washes.

"Every day, I'm living in a fragile state, running on exhaustion ... **I never get a break.** I have to look after him with flu, a bad back or sore arm. It's not his fault, but it's the grind."

NECIC 2012 Sibul Malaysia 3

The Road Not Chosen

After six years of struggling to cope with Callum on her own and being forced to take her council to court for everything from the house they live in to an extra nappy, Asher said she could sympathise with Hill:

"Desperate people do desperate things. I'm strong and determined, but I've had to fight for nappies, housing, transport for Callum and to set up a business. Some people don't have those reserves and it just sends them over the edge."

NECIC 2012 Sibul Malaysia 4

The Road Not Chosen

Julie Evett

Julie Evett, 30, has three daughters, Alanna, 11, and Nicole, 7. Both are healthy girls. Her youngest, Rose, 2, is seriously disabled.

Registered blind, Rose has suspected cerebral palsy, epilepsy and hypotonia, which means that her body is as floppy as a newborn baby's. She cannot turn on to her side on her own or even hold a bottle. She goes to nursery, but increasingly needs one-to-one care.

Julie has called for help from social services four times and has heard nothing. She is asking for a mere two hours' help a day after school.

NECIC 2012 Sibul Malaysia 5

The Road Not Chosen

More than 700,000 families in the UK live with a child with a serious disability. Many of them face daily battles with schools and social services as they seek help.

In Sarawak, we have more than 22,000 families registered with the Welfare Dept. Most of these families need help, but do not know where to go for help.

NECIC 2012 Sibul Malaysia 6

The Road Not Chosen

Parenting a Child With Special Needs

Being told that your child has special needs can seem like the end of the world for many parents.

Here are a few tips to help you survive the trauma

NECIC 2012 Sibul Malaysia

7

THE ROAD NOT CHOSEN

#1

Don't Give Up



NECIC 2012 Sibul Malaysia

8

THE ROAD NOT CHOSEN

9 Join a Support Group



You are not alone

NECIC 2012 Sibul Malaysia

9

THE ROAD NOT CHOSEN

#2

Communicate Your feelings

Talk to your mother, spouse, family member or friend.



NECIC 2012 Sibul Malaysia

10

Communicate your feelings

1. We are built to vocalize feelings and tell our stories. This is an inherent and normal human response. Its purpose is to relieve the stress of trauma and massive change that occur in every life. There is a basic human need to externalize the pressure and pain that develops within.
2. What is the alternative when we bottle the anxiety, anger, fear, guilt or pain that is generated by a major loss? The physical self pays a huge price to perform this task. Stress hormones go into overdrive and every cell in the body is affected. Every cell in the body is heavily stressed. Energy stores are depleted.

NECIC 2012 Sibul Malaysia

11

3. A more vicious result of stuffing feelings is that our unconscious and our memory banks keep them forever alive in full force. Consequently, we are easily thrown into deep pain throughout life when something we see in a movie or on a TV show or read in the paper, cues up the terrible feelings and memories we never dealt with.

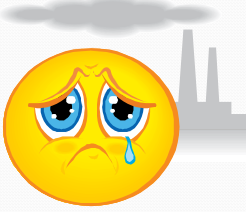
NECIC 2012 Sibul Malaysia

12

THE ROAD NOT CHOSEN

#3

Hence, do not suppress Your Emotions



NECIC 2012 SibU Malaysia 13

THE ROAD NOT CHOSEN

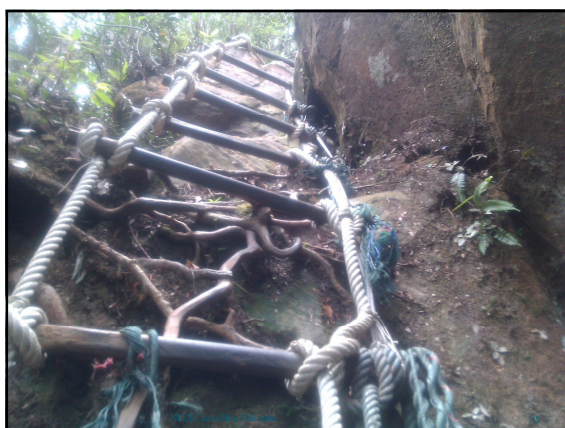
#4

Take One Step at A time

Sometimes we can be so overcome by the amount of work and the number of problems that we become immobilized..

Get through each day one step at a time.

NECIC 2012 SibU Malaysia 14



THE ROAD NOT CHOSEN

#5 Be Strong




Carrot, egg and coffee – what are you?

NECIC 2012 SibU Malaysia 16

THE ROAD NOT CHOSEN

#8

Do Your Homework



Early intervention is important – follow up rehabilitation exercises at home

NECIC 2012 SibU Malaysia 17

THE ROAD NOT CHOSEN

#7 Be Alert




Watch out for changes in your child's diet, sleeping patterns, behaviour, work closely with your doctor

NECIC 2012 SibU Malaysia 18

THE ROAD NOT CHOSEN

#6

Don't compare your child with others



Every child is unique

NECIC 2012 Sibul Malaysia 19

THE ROAD NOT CHOSEN

10 Be Positive +

Focusing on the positive makes life easier to cope with

"Welcome to Athens"

NECIC 2012 Sibul Malaysia 20

Life goes on ...



NECIC 2012 Sibul Malaysia 21