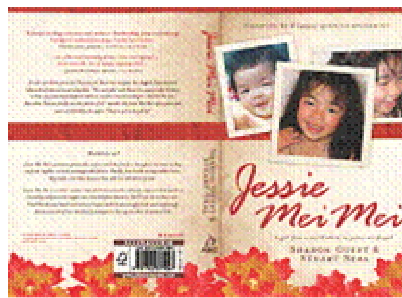


## A family's challenge to bureaucratic madness

A few years ago ABC Four Corners relayed our shocking story. We have now written a book which I thought some of you may like to know about. It is called 'Jessie Mei Mei – A Girl From A World Where No Games Are Played' by Sharon Guest & Stuart Neal, published by Allen & Unwin.

Caroline Jones, Australian Story said: *"A family's challenge to bureaucratic madness – heartbreaking, endearing and funny. A profound Australian love story; I couldn't put it down."*

Quentin McDermott, ABC Four Corners said: *"...one of the most harrowing stories I have ever reported...At its core is the love of a pure, inspiring child..."*



Jessie, our daughter, seemingly healthy, was adopted from China at 20 months. At 3 she was diagnosed with a disability that left us shell-shocked; at 4 another diagnosed disability left us on our knees. Could anything be worse? Yes. At 5 we learned Jessie had a degenerative genetic condition that is gobsmacking in its cruelty. She would not see out her twelfth birthday. Apart from this horrific news we were told: 'Sanfillipo Syndrome' is one of the hardest disabilities to care for. Jessie would develop severe behavioural difficulties and an inability to sleep - eventually she wouldn't sleep at all.

No pain could be worse. We were mistaken. The only way to get help, we were told, was to relinquish our little girl to DoCS (community services). Eventually we could not cope and found ourselves in a world where authorities find it hard to distinguish loving parents from those who abuse their child.

It was wrong. We fought back. We fought for Jessie's rights and our own. We would have still been fighting had we not prevailed and managed to achieve something we were told was impossible.

'Jessie Mei Mei: A girl from a world where no games are played', is co-written by myself (Sharon Guest) and my husband, Stuart Neal. It is a book about our journey: from adopting Jessie and the failings and banality we encountered in the world of the international adoption to going to China and seeing inside Chinese orphanages. It also encompasses the frightening world of DoCS (Community services) where we finally understood how children could die who were known to them and the tragic shortcomings of our disability 'services'.

This book was heartbreaking to write but we wrote it with total honesty in the hope that it would bring awareness to others and for us to try, in our small way, to instigate change in the world of disabilities.

Our interview on Life Matters can be heard by visiting the following website: *Life Matters*: <http://www.abc.net.au/rn/lifematters/stories/2010/2935172.htm>

'Jessie Mei Mei' can be found in most major book stores. You can also purchase it on line. Some of these links are listed below:

#### **BORDERS**

<http://www.borders.com.au/book/jessie-mei-mei-a-girl-from-a-world-where-no-games-are-played/9746353/>

#### **ABC SHOPS**

<http://shop.abc.net.au/browse/searchresult.asp?SearchID=3716139&SearchRefineID=7743163&KeyWord=Jessie+Mei+Mei>

#### **BOOKTOPIA**

<http://www.booktopia.com.au/jessie-mei-mei-a-girl-from-a-world-where-no-games-are-played/prod9781742371047.html>

#### **GLEEBOOKS**

[http://www.gleebooks.com.au/default.asp?p=displaybook\\_asp&bookId=108878&from=search](http://www.gleebooks.com.au/default.asp?p=displaybook_asp&bookId=108878&from=search)

#### **ALLEN AND UNWIN**

<http://www.allenandunwin.com/default.aspx?page=94&book=9781742371047>