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Challenge: Trauma and Recovery in YA Fiction



Butterflies

by Susanne Gervay

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ABOUT THE BOOK: Starred Review from School Library Journal

Every survivor has a story. Often the story is of interest, and even more often instructive. “Butterflies” is the story of a burn survivor, and is both interesting and instructive. It explores the complex areas of the emotional impact of a burn on the individual and family while giving insight into the world of hospitals, patients and doctors. It traces the development of the personality from insecurity and relative isolation to a healthier level of self esteem that enables the individual to form balanced relationships with family and friends. It shows how the inner person can triumph over a preoccupation with surface scars and know that basic values of commitment, caring and trust are more important than the texture of the skin.

“Butterflies” has relevance outside the narrow circle of burn survivors and their families. It shows the ebb and flow of emotions that affect us all, particularly in the transition between childhood and adulthood, and how parenting and family life make these bearable.

Those of us who are involved in the world of burns know how survivors need help from time to time, but slowly develop a depth of character and an inner strength which is rarely seen in others. Like tempering steel, the process of passing through the fire helps make a person of exceptional quality. "Butterflies" captures these subtleties for the reader, and gives a stunning insight into a difficult topic.

Dr Hugh Martin OAM

*President of the Australian and New Zealand Burn Association and
Head of the Burn Unit, The Children's Hospital Westmead, Sydney.*

'Heart wrenching and beautiful are the two words that immediately came to mind as I read "Butterflies." The true terror and depth of Katherine's burns and recovery are deftly shown through the movement of the text between flashbacks and the present. Gervay paints a picture of Katherine as she grows and changes allowing the reader to believe in her as a real person. Unlike other teen angst books, Katherine does not dwell in her angst, but moves beyond it and chooses to leave the misery and find joy in her daily life. Gervay has done an excellent job of examining a topic not often seen in books for young adults- burn survivors who are not victims, but victors. Gervay allows Katherine to win at the end- not because she suddenly becomes amazingly beautiful, but because she always was beautiful and knew that within herself. Kudos to Gervay for painting the reader a picture of a self-reliant teen girl who does not depend on a boy to make herself feel valuable. Highly recommended for libraries- school, public and personal- who want to add to their girl power collections.

SWON Libraries. Kenton County Public Library webmanager@swonlibraries.org

ISSUES AND THEMES:

Feedback: susanne, before reading butterflies i thought the only way to be pretty was to be perfect, the hair the face the looks, but it's not true, i read butterflies in 3 days, i couldn't put it down, it made me really feel good about myself, and think about what it would be like if i was katherine, she went through alot and knew in the end that if she didn't turn out perfect, it didn't matter, she learnt to be grateful to be alive and live with her burns. It's was one of the best books i have ever read, thankyou for giving me a masterpiece to read

Source: Susanne's books: Blog: -Confirm: 56 SUBMIT: Submit

1. Impact of burns/disability on an individual and family
 - Survival
 - Disfigurement
 - Impact on a child's growth and development
 - Prolonged hospitalization and years of surgery
 - Pressure on the family
 - Living in two worlds – the hospital and the outside world
 - Emotional, psychological and physical impact of burns on the family
 - The role of the Burn Unit team such as the Unit at the Children's Hospital, Westmead; the family; and support groups.
 - Rehabilitation and return to normal or near normal life
 - Role of the community in developing tolerance and understanding

2. To look beyond surface scars and find the person inside.

A burn victim has the same search for identity as those who are not burnt. However it requires strength and courage to meet those challenges. Set against burns, *Butterflies* explores Katherine's search for identity:-

- Independence
- Sexuality
- Family
- Friends
- Career
- A future

3. “Challenges are faced by each of us, every day of our life. Those ‘challenges’ are greater for some than others.” ..says Louise Savage, the remarkable World Sports person of the Year with a Disability who endorses *Butterflies*.

Butterflies is about the courage and strength to meet and overcome those challenges. Burns is a specific challenge, yet it is also representative of all those hardships individuals face – be it:

- intellectual disability
- physical disability
- emotional illness
- social challenges, such as conflict within the family, violence, divorce
- political hardships such as war, migration

Or it may be the personal but often difficult challenge of growing up and finding your place in the world:-

- relating to family
- coping with examinations
- relationships
- hopes and expectations
- developing self esteem

Butterflies harnesses an individual's strengths to overcome & celebrate the challenges of life.

4. People do not exist in isolation. In *Butterflies* the issue of dependence –independence of a young person moving from childhood to adulthood is heightened through Katherine being burnt. It explores:-
- the strength and need for family support
 - the values of family and how it translates to the children
 - the struggle to gain independence by the young adult
 - the establishment of an adult relationship by the child with the parent
5. What is disability?
- Should a person be treated differently?
 - Are they ‘less’ than a normal person or ‘more’?
 - How does society deal with disability?

Butterflies: Youth Literature as a Powerful Tool in Understanding Disability

Disability Studies Quarterly ; Winter <http://dsq-sds.org/article/view/844/1019> Disability Studies;
Extract from article by Susanne Gervay

The Process of writing Challenge, trauma and recovery in YA Fiction

I continued a process that would take six months of research. I needed to understand burns from a medical perspective before I could seriously grapple with a novel. I trawled through the huge second-hand bookshop in Sydney's student area and emerged with two heavy medical books on burns. I found the graphic nature of the pictures of burns, grafts, scarring, and loss of body parts was horrific. In some, the faces of people had become unrecognisable and I had to cover these photos with one hand as I read, so that I could cope. I underlined key concepts, wrote notes and read and re-read the text. Burns are complex, and I am not a doctor. Doubts about my ability to correctly understand the medical process undermined my confidence. That is when I started my visits. My first visit was to see Professor Wayne Morrison, Director of the Bernard O'Brien Institute of Microsurgery at St Vincent's Hospital Melbourne ... Professor Morrison explained the process of burns and the surgery, the complexity of reconstruction. He gave me answers to questions I did not have the experience to formulate. Later I visited Dr Hugh Martin, Head of the Burn Unit at the Children's Hospital, Westmead in Sydney. Dr Hugh Martin lectured me on burns, grafts, pain control, scarring, and survival. There were diagrams and explanations and I began to really understand the trauma of a major burn and the huge and lengthy challenges facing burn survivors, their families, community and the medical and support teams. As Professor Morrison and Dr Hugh Martin spoke to me, it was as though my escape routes were closing. How could I avoid writing *Butterflies*? As these men gave so generously of their time, I realized that I was trapped. I had to write this book.

I spent many hours talking to social workers, physiotherapists, nutritionists and nurses committed to assimilating burn survivors into normal life and helping the family cope with the trauma and many years of operations that would follow. I investigated the Burn Unit in The Children's Hospital, Westmead with its routines of bandages, heat lamps, dressing and undressing wounds, the creams, the pressure suits, and the processes of healing. The commitment of the family to their burned child was revealing—the daily dressing, physiotherapy, and care. I saw social workers helping the burn victim, parents and siblings. There are often complex emotions and issues to be dealt with including guilt by parents about how their child became burnt, which can lead to breakdown in family relationships and resentment over the long and arduous support needed to help the child. There can be sibling anger at becoming marginalized, and anger and fear by the burn victim over the disability and the processes involved in becoming independent.

I discovered the Burn Support Foundation, where parents created a community for their children and the families of burn victims. There are newsletters and socials. The highlight is the burn camps sponsored by the New South Wales Fire Brigades, where children in pressure suits and splints, with their scars and restrictions can play without the fear of being socially ostracized.

I interviewed children who had been burnt. I was seeking to discover how burns impacted on the cognitive, personal-social, psychosexual, moral and needs development of young people. This was a long and exhausting process of interviews. Typical comments were:

Adolescents. "I feel like nothing sometimes." "I don't care about the burns. People have to take me as I am." "I dream about being normal all the time. I just wish that I could be." "I feel scared a lot of the time." "I want a boyfriend but who'd want me?" "I'm sick of the pain. Sick of it." "I hate people staring." "I'm as good as anyone else." "Mum wants to control everything." "My friends don't get it." "I wish I was normal." "I miss a lot of school. Makes me feel dumb." "Mum doesn't get it. I can do things for myself." "Hate being called disabled."

Teenage siblings of burn survivors. "I wish I was the burnt one sometimes." "I've got to help all the time." "People don't get what it's like." "We can never afford anything." "It's not fair." "Sometimes people are cruel to my sister." "I defend my brother." "Dad left us." "We're good mates."

Pre-adolescents. "Mummy goes with me to the hospital." "I don't like the operations." "I hate Mum putting on the cream." "It's fun at camp." (Burn Camp.) "Bad things come in the night." "There's a school in hospital that's fun." "The operations hurt." "I don't have many friends at school." "Kids laugh at me." "No one likes me." "I get lots of presents in hospital." "I like some of the nurses. They're kind, but some are horrible. They have needles." "I just want to play soccer."

I sought to understand the emotional journey of burns from the point of view of the burn survivor, a child at different ages, and the siblings. In addition, I interviewed parents and discovered that many had serious problems with guilt over the burn incident; exhaustion and anger at the dedication needed to help their child; a profound need to protect their child; serious difficulties in maintaining the family unit, and fear of letting go their child.

Younger children with severe burns were very dependent on their main carer, usually the mother. The carer's issues generally centred around safety, acceptance, the immediate experience of surgeries, recovery, school, and family. When there was not any surgery and the children felt better, they played and laughed. Younger children reacted to the immediate impact of their environment. Adolescence presented greater challenges as young people faced issues of identity, peer group pressure, dependence versus independence, sexuality, self-esteem, acceptance of self, individuality, the search for understanding of the world and their place in it. These issues of adolescence were heightened by the impact of burns. Unlike the younger children, adolescents brooded over their situation and worried about the future.

When I finally felt that I understood the experience of burns, the medical facts and the social aspects, the viewpoint of the burn victim and survivor, the family's perspective, the role of health workers and the community, when the emotional experience of burns was internalized and melded into my own personal experience of growing up, then I put away the research. Only then did I begin the yearlong journey of writing *Butterflies*.

I had a definite agenda. *Butterflies* would be medically accurate, but it would not be a medical book. It would be psychologically accurate in terms of child growth and development, but not a didactic textbook. It would reflect the stories and journeys of the young people and families whom I had interviewed. I wanted to write a story where disability is part of the fabric of life, but not life itself. The main character Katherine would be burnt but never be a one-dimensional stereotype. Katherine would be complex like all human beings with a real family, a background and a personality that reaches from the page into the lives of readers. Katherine's life would show that disability does not separate burn survivors from the community, but unites them in the common bond of humanity. *Butterflies* would be good literature and a powerful tool in understanding disability.