

Melanie
Bird With A Broken Wing
A Mother's Story
By: Beth Harry

Presentation created by:
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Characters-

- Beth- Main character, mother
- Clive- Beth's husband
- Melanie- Newborn with cerebral palsy
- Paula- Clive's Niece
- Dr. McDowall- Melanie's pediatrician



Paris le 21 Août 1851

Part I, Chapter 1

- The story begins with a baby being born at 4 ½ pounds.
- From the moment she is born, Melanie's mother knows something is wrong with the baby. She does not attempt to see her baby for 24 hours after birth, which is not normal!
- The doctors found several problems the baby was having: she was physically weak, could not breathe on her own, could not suck, and could not swallow.
- Many emotions were running through Beth's mind. She quoted, "I went to the nursery, and there she was, beautiful and still, and the words that filled my mind remain one of my most terrible memories: *You are beautiful, but if you're going to hang around and give me trouble, I'd rather you died.*" (Harry, pg.4)



The background is a collage of vintage elements. It features a light-colored, floral-patterned paper with a repeating leaf and flower motif. On the left and right sides, there are strips of aged, yellowed paper with handwritten cursive text. A small, detailed illustration of a bird perched on a branch is positioned on the left side, overlapping the floral paper and the handwritten text. The overall aesthetic is that of an antique or historical document.

Something to think about:

Beth had many confusing and negative emotions after Melanie's birth. If you found out your new born baby had several physical problems how would you feel? How would you cope?

Chapter 2

- Beth continues to address Melanie as “her”, instead of her name.
- Beth has 2 big questions that she asks the doctor:
 - 1- Was her baby’s brain damaged?
 - 2- If there was too much oxygen in the incubator where Melanie remained, would she become blind as a side effect?

The doctor says her brain seems to be underdeveloped and also reassured Beth, that the air in Melanie’s incubator was at the perfect level.

Beth relies on prayer and the Lord:

I will lift up mine eyes unto the hills, from whence cometh my help, my help cometh from the Lord, who made Heaven and earth? –Psalm 121:1-2



Chapter 3

- Beth begins to feel “robbed and cheated by her own body.” How could something so different come from a perfectly healthy body?
- Paula (Clive’s niece) comes to stay with Beth for a few days. Beth begins to express her emotions to Paula. She tells Paula she can deal with any type of disability, EXCEPT mental retardation.
- As a wife, Beth does not want to express her emotions and feelings to her husband. She does not want to burden him and knows that he prefers not to discuss the situation at hand.
- Melanie was hooked up to a feeding tube because she was unable to “suck” from a bottle. The tube went into her nose, down her esophagus, and into her stomach.
- Finally, she was able to breath on her own and breathing normal air!



Paris to Clive



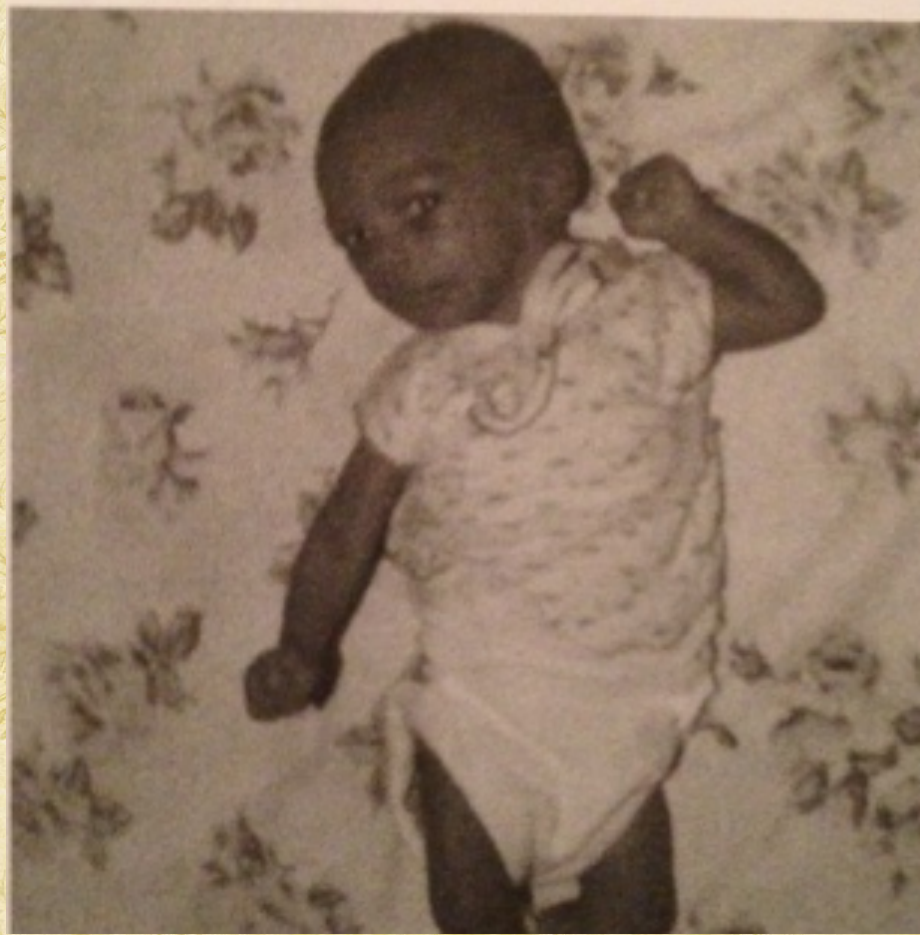
Actual picture of Melanie at 2 weeks old with her mother Beth. (Harry, pg.9)

Chapter 4

- This was the beginning of the most difficult time in Beth's life. Her anxiety levels were rising daily.
- Her mind constantly raced with questions about Melanie: *Was Melanie alright? Would she have gained an ounce of weight? What kind of night might she have had?*
- The only way Beth thought she could help Melanie was by producing breast milk. Her milk supply slowly dwindled. Which upset her very badly.
- Melanie's eyes remained fixed in one position and her limbs would become stiff. Her body position was referred to as 'asymmetric tonic reflex (ATNR).



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Melanie at 5 months showing the ATNR posture (Harry, pg.15)

Chapter 5

- After a few weeks had past, Beth's feelings towards Melanie remained the same.
- *"I never doubted my love for her but often doubted my ability, even my willingness, to cope with the situation I found myself in."* (Harry, pg. 16)
- Beth's dream: A lizard in her house turned into a large crocodile that was extremely ugly. She was scared of this creature, yet went after it with a large stick. The crocodile became afraid of her.
- She had previously done research on interpreting dreams. She concluded that, *"The dream is me. Therefore, the house is me. The 'I' of the dream is me. The Lizard-Crocodile is me!"* (Harry, pg. 19)
- The dream represented a battle within herself.



Chapter 6

- Clive and Beth finally met Melanie's pediatrician. Most likely avoiding him because of their fear in personally hearing his diagnoses'.
- Dr. McDowall explained that Melanie's limbs had an abnormal stiffness of the muscles when moving. He continued to say this was because Melanie had brain damage.
- Her condition was known as cerebral palsy.
- Melanie would suffer from some degree of physical handicap, but her mental development could be perfectly normal.

Are you familiar with cerebral palsy? What characteristics have you seen with children or adults with this disability?



Chapter 7

- The midwife, Venus, taught Beth how to spoon feed Melanie.
- There were several tough steps to successfully feed her: getting her tightly closed lips to open, relaxing her jaw so Beth could get the spoon in Melanie's mouth, then helping her relax her tongue to help with swallowing.
- After feeding her, they began to hear a rattling noise in her throat. Doctors concluded that Melanie was having trouble swallowing, so had to regress back to tube feeding.
- It was agreed that Melanie would return to her real home on Thursday October 30th, 1975.



Chapter 8

- After Melanie returned home, Clive and Beth found out how much effort the nurses and doctors had put into feeding Melanie. It took 1 whole hour to feed Melanie 2 ounces of milk!
- After a long 5 days of Melanie being home she began vomiting.
- Beth placed her in her bed and laid her on her back due to the excessive vomiting. A mother's worst nightmare came to life as Beth walked back in the room to find Melanie on her back choking on her vomit.
- As Melanie was unable to breathe and gasping for air, Clive and Beth took her to the hospital. She eventually was able to catch her breath
- She was placed under medical care once again for a couple of weeks.



Chapter 9

- After being in the hospital for another 2 weeks, Melanie was finally able to go home for good.
- She began to vomit on the milk when being fed now rather than choking on it.
- Beth was still worried about Melanie's physical issues. Often times Melanie would be staring directly at Beth, but if Beth moved to one side or another Melanie's eyes would not follow. They would remain fixed in one spot.
- She always seemed to be frowning, but regardless of all the things NOT working or looking correctly, Beth was glad her baby was finally home.



Chapter 10

- Beth began to reflect on her relationship with Clive.
- Clive was born in a family with 11 other siblings. He grew up in Trinidad.
- Beth had African and European origins.
- They met at the University of Toronto during their first year of philosophy.
- Beth earned her bachelor's degree in English Language and Literature.
- After earning her masters degree she became a teacher at the University of the West Indies and served as a lecturer for new high school teachers.
- During the time of Melanie's birth, she was on maternity leave.



Chapters 11-15

- Beth accepted that her baby had brain damage, but it frustrated her when other people could not accept that. They would say, “I don’t believe it, she’ll be alright!” (Harry, pg 49)
- Beth continued to ask the doctors many questions about Melanie; Why she was drooling? Why she was gargling liquids in her throat? She was stuck between two emotions. Wanting to know, and not wanting to know typical of many parents in her position.
- At 6 months the doctor concluded that Melanie’s mental retardation was severe.
- They finally found a food thickening agent called Nestarigel, which helped STOP Melanie’s vomiting!
- At 7 months old Melanie smiled to Clive whistling. Such a small physical gesture filled such a large void in Beth and Clive's hearts.



Chapters 16-20

- Once Melanie and Beth moved to Toronto they visited the OCCC (Ontario Crippled children's Center)
- Beth had many appointments for Melanie with an ophthalmologist, neurologist, and pediatrician.

Beth began working as a volunteer in the OCCC school. She worked on developing awareness and response in 8 children with severe disabilities.



Melanie began developing small physical abilities. She was able to grab for things. This picture is Melanie grabbing for her mother's face at age 1.

Chapters 21-25

- Beth continued volunteering at OCCC on Mondays and Thursdays. She also began teaching at Centennial Community College. Teaching and continuing her old routines was the best therapy Beth could have.
- Melanie began vomiting again and had to go back to tube feeding. Beth took a step forward and learned how to insert the tube herself.
- Another issue arose with Melanie's health. She was suffering from severe electrolyte imbalance, somewhat similar to dehydration.
- After many different procedures it was concluded that the only way to feed Melanie and keep the food down, was to feed her while she slept.
- At 1 year and 4 months, Melanie was now able to move, cry, smile, see, hear, and recognize people.



Chapters 26-28

- Clive and Beth received genetic counseling to assure that Melanie's disabilities was not genetic. They decided embark on a new pregnancy!
- Beth reflects on Melanie's improvements by looking back at her journal notes.

Age 2

Diary Entries



Participates in and enjoys social games (peek-a-boo, clap hands, etc.).	Smiles and squeals in "peek-a-boo" and other games, e.g., "up and down," "fall down." Smiles in response to names of songs. Opens hands for snapping.	July 1 July 20 August
Responds to instructions.	"Come to Mummy,"—arms outstretched. "Come here,"—rolls across room to Mummy. "Open your mouth,"—opens. "Look at Mummy,"—stares, looks. "Touch," e.g., a toy. "Put," "Push." "Open your fingers."	March 28 June 15 April June July-August July-August July-August
Responds to ritual phrases ("Pretty!" "Bye-bye").	Beginning to lift hand and wiggle fingers in response to "Bye-bye." Waves "Bye-bye."	August 12 End of August
Associates "Daddy," "Mummy" appropriately.	Turns, looks at Daddy in response to word. Turns, looks at Mummy in response to word.	June July
Associates sounds with relevant objects (keys, door opening, car starting).	Reaches for correct object on hearing sound, e.g., squeaky toy, bell, music box. Turns appropriately on hearing door, car, footsteps.	Mid-June July
Associates names with relevant objects (daddy, ball, car, bed, water, etc).	In response to the question, "Where is the...?" turns, looks, and reaches for: brush, bed, eyes, nose, mouth, hair, water, soap.	End of June
Associates names...	Ear, tongue, teeth, necktie, frigate, fridge, vase, book. Milk, juice, spoon, dolly, bottle, comb, light, mirror, box, bread, car.	End of July Mid-August
Gestures for communication.	Waves "Bye-bye." Raises hands on hearing "Come." Reaches for bottle at feeding time.	End of August March June
Puts out hand for putting on blouse.	Pushes arm through sleeve.	August
Settling.	Smiles at daddy's smial home.	Mid-August
Face more relaxed and expressive.	Improving, more smiles—but...	July-August
Inflates syllable sounds.		
Makes syllable sounds in relation to people, objects.		

Part II, Chapters 28-30

- Their second child, Mark was born! He was a healthy baby!



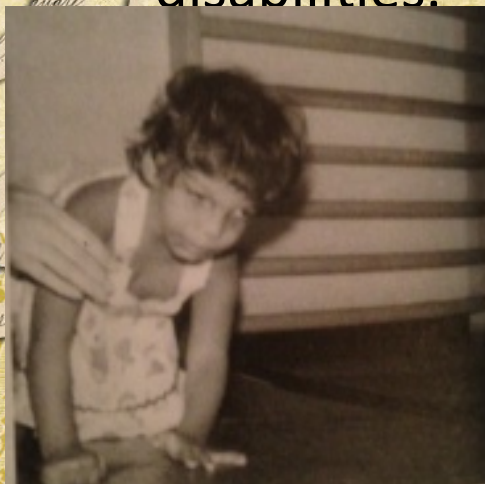
- Clive was offered a job in Barbados for 2 months. Beth knew she could not take care of 2 babies by herself so decided to move back to Jamaica with her parents.

Chapters 31-35

- Beth wanted to create a play group for Melanie. After searching for other children and families to participate, Beth found Joan Knowles and Wendy Gomez. They had a small clinic that offered speech and physical therapy to children with disabilities. The only thing they needed was a teacher. Beth soon became part of this wonderful organization.
- Children at this clinic ranged with disabilities from down syndrome, moderate retardation, hearing impairments, cerebral palsy, and intellectual disabilities.

Melanie was developing physically.

Melanie at 3 ½ years old



Chapters 36-38

- Clive was assigned to another job in Toronto. Beth's father had passed away so Beth's mother was the only other form of family support.
- Beth quit working at the Immortelle Center because it was too much work to raise 2 children on top of working.
- At this time Melanie was able to stand up while leaning against furniture, and was aware of other children around her.
- During the summer, Melanie went to day camp at Spring Garden Summer Recreation Project for Multiple Handicap Children.
- During her journaling, Beth took time to thank many special people in her life including Venus, the midwife at the maternity clinic; Joan, Wendy, and Deidre from the Immortelle Center; and Sarah from Toronto.



Chapters 39-40

- Beth was currently a full time student receiving a degree in Education of Exceptional Students at York University.
- During her course work, she was able to visit special education services and programs around Toronto.
- She planned to transfer this knowledge into action back at the Immortelle Center back home.
- Melanie still had trouble squinting and had a drifting eye. The Ophthalmologist suggested surgery would correct this issue.
- After recovering, the surgery had helped Melanie focus more precisely. People could now tell what Melanie was looking at.



Chapters 40-45

- A psychological assessment was done on Melanie to conclude her comprehension level.
- Her comprehension level at age 4 was comparable to a 2 year olds. This concluded that Melanie was in the range of moderate retardation.
- “I felt a rush of awe and hope as it finally dawned on me that when I looked at Melanie, I must think not of what a normally developing 4-year old should look like but of what a 4-year-old with severe cerebral palsy might look like” (Harry, pg. 172).
- As time passed, the Immortelle Center thrived, and so did Melanie.
- She was able to shake her heard for the *no* response.
- Although her receptive abilities were improving, she was still struggling to make sounds.





Melanie at 5 years old. (Harry, pg. 190)

Chapters 46-51

From Fairy Tale to Nightmare



“Mercedes is feeding Melanie, and she is choking.”

“Sandra, tell her to put Melanie’s back against her chest, place a fist under her diaphragm, and pound upward on the fist with the other hand. That will force air up into her throat, and the food will come out.”

(Harry, pg.195)

- Beth and her son Mark were 20-30 minutes away because of traffic. Beth finally reached Mercedes, Sandra, and Melanie. They all jumped in Beth’s car and rushed Melanie to the doctor.

- Melanie was laid down on a bed with an oxygen mask. The doctor began pumping her chest.

“The doctor stopped, took off his stethoscope, and looked at me, shaking his head.” (Harry, pg.199)

Chapters 50-51

- Beth reassured Mercedes that it was not her fault. It was a miracle that Melanie had lived that long.

“We have nothing to regret, Mercedes, no fault to find, no guilt to bear, only the pain of losing her and we will have to live through that.” (Harry, pg.202)

- At her funeral, her Uncle Phillip made a beautiful speech.



Paris, le 21 Août 1851

The news of your passing has brought many memories to mind, as well as much profound grief to me. When I remember the circumstances of your brief stay, I am amazed at the enormous impact you have made on our lives and the equally enormous legacy of lessons you have left with us. Although I am sad to think that I will never see you again, I am happy and proud to have been a part of your life, and find some consolation in the knowledge that you will continue to live in the lessons we have learned from you.

Your lessons are as extraordinary as the extraordinary love you received from your extraordinary parents. Your life is a tribute to their love and your lessons a blessing to the many who received them.

I am thankful for your life, and am with you today as much as your lessons are with me, forever.

In loving memory, Uncle Philip

EPILOGUE

- Beth became a professor in special education at a University in the United States.
- Mercedes became a nurse in Trinidad. Melanie's death has enriched her life as a nurse.

Beth's interest and dedication as a researcher and teacher have grown because of this experience.

- The Immortelle Center has remained a nonprofit organization.



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Reader's Guide (Harry, pg.211-214)

How has special education changed since Beth's search for services in the 1970s?

What can professionals in early intervention and early childhood special education learn from Beth in terms of careful observation and record keeping?

[Refer back to the Immortelle Center.] What are the pros and cons of grouping children with similar disabilities verses cross-grouping children of various ability levels?

[Melanie was unable to receive a CT scan until age 4 because of technology] With today's technology, Melanie would have received a CT scan much sooner. Ho would this have changed the course of her treatment?

(Harry, pg. 203)

Cerebral Palsy

Melanie was diagnosed with cerebral palsy

- Before reading this book we had both heard of cerebral palsy but we looked it up to find more information and this is what we found:
- Cerebral palsy is a disorder of movement, muscle tone or posture that is **CAUSED** by the immature, developing brain, most often before birth



Diagnosis

- There are varying times that the symptoms of cerebral palsy may appear. Although it is present at birth symptoms may not appear until later.
- Signs and symptoms appear during infancy or preschool years.
- Cerebral palsy causes impaired movement associated with exaggerated reflexes, floppiness OR rigidity of the limbs and trunk, abnormal posture, involuntary movements etc.
- The symptoms vary and many times seem to be a combination of all of the above.





The effect of cerebral palsy on functional ability varies **GREATLY**

- People with cerebral palsy may have difficulty with swallowing .
- Commonly have eye muscle imbalance.
- People with cerebral palsy may have reduced range of motion due to muscle stiffness. Some people are able to walk while others aren't.
- Some people show normal to almost normal intellectual function, while others may have intellectual disabilities

Symptoms of cerebral palsy

- Variations in muscle tone either too stiff or too floppy (**Spasticity**- stiff muscles and exaggerated reflexes.)

- (**Rigidity**- stiff muscles with normal reflexes.)

- (**Ataxia**-Lack of muscle coordination)

- Tremors or involuntary movements

- (**Athetosis**-Slow, writhing movements)

- Delays in reaching motor skills milestones. Ex:

- Pushing up on arms, sitting up alone or crawling

- Favoring one side of the body, such as reaching with only one hand or dragging a leg while crawling

- Difficulty walking, such as walking on toes, a crouched gait, a scissors-like gait with knees crossing or a wide gait

- Excessive drooling or problems with swallowing

- Difficulty with sucking or eating

- Delays in speech development or difficulty speaking

- Difficulty with precise motions. Ex: picking up a crayon or spoon



Resources if you or someone you know has cerebral palsy

<http://ucp.org>

<http://easterseals.com>

