Lene Andersen

Unbound

By Lene Andersen

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The Story of Unbound

In 2007, a Canadian magazine called Homemakers held a memoir contest for their readers. My mother was the first to spot the notice and she thrust it upon me with an unstated, but very clear directive: write something. Enter.

Being a dutiful daughter, I set about pondering the topic of my memoir. It wasn't long before I realized there was only choice: the moment I was set free. And *Unbound* was born.

Much to my delight, my entry won second place in the contest, and for years it and the other winners lived on the Homemakers website. Whenever someone looked at me sadly, expressing sympathy for my life in a wheelchair, I'd shoot them the link to Unbound. It usually did the trick.

Homemakers is no longer published and my snippet of a memoir lost its home on the web. So I decided to release it as a free publication and here it is.

I hope you like it. And if you use a wheelchair and someone ever looks at you sadly, expressing sympathy for your life, give them a copy.

> Lene Andersen Toronto, July 2013

By today's standards, the wheelchair was small and insubstantial. Two side frames made of steel tubes, connected by folding braces and three squares of cornflower blue leather: a back, a seat and one below to hold the battery. The wheels were small and solid rubber and attached by the right armrest was a box with a joystick – one speed only. The battery was acid-based, instead of the present gel, and at the front in each of several small, side-by-side rectangular compartments, three balls of red, yellow and green were suspended like tiny upside-down traffic lights, indicating how much of the battery charge was left.

By today's standards, it had hardly any power. By today's standards, it was hopelessly inadequate.

And yet, it was a dream come true for me.

I am four in one of my very first memories and we had just moved from an apartment to a house in a suburb of Copenhagen, Denmark. In this memory, I am helping my father paint the living room wall, standing side by side, each with a bucket of white paint at our feet, the golden sun slanting through the window behind us. As we dip our brushes in the thick white liquid and carefully brush the wall, changing the colour to something new and bright and hopeful, I feel grown-up, proud that I am allowed to help with such an important job.

Another of my early memories is the deep pain in my wrist after we had finished painting. It was the first sign of the juvenile arthritis that would at first creep slowly, then start galloping with a burning fury through my body. Leaving destruction in its wake, it fused some joints in fixed positions of deformity, leaving others swollen and racked with pain. It almost killed me when I was twelve and when I went home after another several months in the hospital, I remember the grinding agony in my knees and feet and hips as I walked. I remember the flight of stairs to my classroom, every day gritting my teeth and moving up slowly, pulling on the banister to ease the stress on my legs. Before too long I was back in hospital, using at first crutches, then a loaned wheelchair and then, at last, as the disease fused my hips and I was unable to sit, I lay in bed.

I had just turned 14.

The world shrinks when you are stuck in a hospital bed, narrows to food, to television, to visitors, the days blending into one another, in a parallel otherworld of white uniforms, bedpans and watching the seasons change outside the window.

I was there for a long time, waiting for hip replacements that had to be specially made for me. This was Denmark, a tiny country, almost 30 years ago. Joint replacements came from England then and custom-made hip replacements took time. And so, I lay in bed, in a room with three other beds, watching other girls come and go, their broken bones healed, their surgeries over and still, I stayed on in that bed.

I did my schoolwork there when for an hour or so every day, the hospital's teacher would sit next to me and we would try to keep up with my classmates whom I hadn't seen in years. I made friends, mostly temporary, with the other kids who came, had surgery and went home, giggling after the lights went out with the girl in the bed next to me, having crushes on boys who came in with broken legs, pulling pranks on the nurses. And always I read, the adventures found between the covers of a book breaking the monotony of waiting in the otherworld of white uniforms, bedpans and watching the seasons change outside the window.

I was 16 when I got one hip replaced, then five months later the other. And then came the day they brought the wheelchair to my bedside.

I don't remember being lifted into the chair, nor do I remember what it felt like to sit for the first time in over two years. But I remember impatiently listening to someone explaining how to make the chair work: that I should push the red button and once the chair was on, carefully move the joystick in the direction I wanted to go. I remember a rushing in my mind, the rest of the room blurring, the only clarity me and the wheelchair. I remember my whole body, all of me straining to go, to move. And then finally, after what seemed like hours, someone, I know not who, saying "now try it" and I pushed forward on the joystick and the chair moved and it was as effortless as breathing.

I left the room on my own and without help for the first time since I had been admitted. I pushed the joystick right, the chair turned and I drove down the wide hallway, past the other rooms, only dimly aware of the kids watching me and through the door at the end of the hallway, turning left past a bank of elevators. On the other side, there was an empty ward and I leaned forward, pressed the automatic door opener and went through.

The door closed behind me and I was alone and it was glorious.

I felt no separation between me and the joystick that made the chair go in the direction I wanted, no more careful practice was needed for it were as if the chair and I had been waiting for each other, prepared to join together. As I drove down the wide corridor, past darkened rooms and empty beds, in solitude and silence for the first time in years, the chair became my legs and I no longer drove; I walked.

And when I re-entered the ward from which I came, walking past the staff, they smiled widely in surprise, congratulating me and I can still feel the triumphant grin I wore those three decades ago as I came from silence into noise. I felt reborn, no longer trapped in bed, waiting for others to bring me what I needed, but now a person who could get it for myself.

In that chair and in its so far three successors, I have moved to Canada, gone to university, worked, danced, held my sister's babies, lived in my own apartment, bought groceries, volunteered, paid taxes, sat by my father's bed as he died, loved and cried and laughed and lived. Strangers tell me earnestly that they would kill themselves should they lose the use of their legs and I am ever surprised to the point of speechlessness that they are so blinded by the lack of walking they see only constraint and limitation. That they cannot see there are no ropes to bind me in place; that this chair with wheels gives me wings to fly.

THE END

About the Author

Lene Andersen is an award-winning writer, disability and health activist and photographer. She lives in Toronto close to the lake where she shares her home with a cat and too many books. Lene is also the author of

Your Life with Rheumatoid Arthritis: Tools for Managing Treatment, Side Effects and Pain.

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Come By and Say Hi!

Lene blogs about RA, disability and life, the universe and everything on her blog <u>The Seated View</u>. You can also follow her on <u>Twitter</u>, connect on <u>Facebook</u> or send her an email at <u>lene@yourlifewithra.com</u>.