

In *Lock Me Up or Let Me Go*, her second book of memoirs, Betty Krawczyk writes about the death from breast cancer of her 27-year-old daughter Barbara Ellen.

The last migraine I had was in the palliative care unit almost 3 years ago. When the doctor in charge told me that I should tell Barbara Ellen it was okay for her to die. 'She wants your permission to die.' he said gently. We were in the private room reserve especially for people like me, the most wretched people of the earth. 'To hell with that!' I flung at him, shocked and horrified at the very suggestion. 'She doesn't have my permission to die, I forbid it.' I had broken down at that point and was sobbing wildly. The doctor waited patiently. He was used to this reaction. That was his job. 'Mrs Krawczyk. I think you understand that Barbara Ellen's suffering will simply increase now by the hour.' 'She is not suffering. She has a butterfly in her arm. She talked to her sisters and her father this morning. She saw friends just yesterday. She was talking to her little boy and hugging him.' 'That was a gift. A gift she gave loved ones to tell everybody goodbye. You're the only ones she hasn't told goodbye. She wants to do this now. She wants your permission to leave.' 'Who do you think you are God? How do you know this is the hour of her death?' And then I was reduced to begging. 'Give me a few more hours please. Please put the IV back in.' 'She doesn't want it. You have to be strong enough to give your daughter what she wants right now. She needs you to help her to let her go; the only way you can help her now is to let her go.' The headache was so bad I thought I might expire before Barbara Ellen did but I didn't. By the following evening I had recuperated enough to tell my daughter that if she was tired of being sick and wanted to go, I would no longer try to keep her. She held my hand and told me she would wait for me wherever it was that she was going and she died that morning in my arms, her sister Marion holding her, too, her father also by her side.

I was the palliative physician in that scene. I well recall Barbara Ellen huddled in her hospital bed under the window, in the first room on the right of the hall as you entered the ward from the elevator. Slight to begin with, she had been reduced to a waif-like size by her terminal cancer. She said very little and she seemed sad. I had no knowledge of her history except for the essential details of her disease. She had been diagnosed with inflammatory breast cancer, a type that strikes young women and has a dismally poor prognosis. She had elected to refuse conventional medical treatment - not an entirely unreasonable decision considering her diagnosis but highly unusual. Such decisions always involve more than the bare medical facts, and my sense was that this young woman felt quite isolated - had felt that way all her life. At times I just wanted to cradle and comfort her in my arms as one would an infant or small child.

I had talked with Barbara Ellen after morning rounds on the day Betty depicts in her memoir. 'How much longer do I have?' she asked.

'Not long. How does it feel to you?'

'I've had enough. Are you giving me anything to keep me alive.'

'Only the IV. Without the fluids you would die in a day or two. Would you like us to stop it?'

'My mother couldn't handle that.'

'I get the feeling You always took care of her in some ways, so it may be difficult for you to do what you want now, you don't need to take care of her any more. What would you do if you could just take care of yourself?'

'I would take out the IV.'

'I respect your mother feelings. This is extremely hard on a parent. I can only imagine how unbearably difficult. But you are my patient here and my primary responsibility is to you. If you wish I will speak with her.'

Recently, Betty Krawczyk and I met again to talk about her daughter's life and death. We had conversed briefly after Barbara Ellen died when Betty was grieving and attempting to comprehend why her daughter had died so much before her time. I had recounted for her my understanding about the possible connection between a stressful early childhood and increased risk for the later development of cancer. Soon afterwards, I received the mail a copy of her memoir *Clayoquot: The Sound of My Heart*. Inside the cover was an inscription 'Herewith my book. It explains something of my relationship with my daughter who died of breast cancer April 30 in your unit.' Having read that book, I hoped Betty would agree to be interviewed for *When the Body Says No*. As it turned out Betty had been thinking of me having just written the passage quoted above. She was interested in learning more about my perspective and hoped I might help her understand better some of the things Barbara Ellen has said in the last six months of her life.

It was no ordinary discussion Betty and I had, but Betty is no ordinary woman. She is well known in British Columbia and beyond for her activism in environmental causes. The title of her first book refers to an internationally renowned rainforest preserve on the West Coast, Clayoquot Sound, threatened some years ago by logging interests. In September 2001 73-year-old Betty was incarcerated for four and a half months for criminal contempt of court following another logging protest.

Although *Clayoquot* is mostly about Betty's experiences as an environmental crusader, she also gives a vivid and honest history of her personal life. With four husbands and eight children, she's had an eventful life. Now Betty acts a surrogate mother to Barbara Ellen's son Julian, who was only two when his mother passed away.

Barbara Ellen gave vent to frequent expressions of deep anger at her mother in the final six months before she died. It is that anger Betty was still struggling to understand.

Betty Krawczyk was born in Southern Louisiana, which at that time she says was 'mostly one big swamp.' 'I wasn't raised to be a protester.' she writes in her book. 'I was raised a poor country southern white woman.'

Memory is so selective, so subjective. At a sibling confab several years ago we were tickled and somewhat amazed to learn that we each, my brother and sister and I, had felt the others to be favoured in the family. I know I felt the other two to have been favoured. Actually I still do. My brother was the older and the only boy, so he got most of the attention. What was left went to my sister because she was the baby and delicate to boot. I was a big healthy girl who could amuse herself so nobody took any special notice of me, which was just fine as far as I was

concerned. You really didn't want my father to notice you. If he did, you were in trouble. Not that he beat any of us ever, but the threat was always there. We were there to be seen not heard, and seen as little as possible. My mother was different. She was warm and loving. Although I always knew she favoured my brother and sister, she was so full of love some of it slopped over on me, too. After I grew up, I once confronted my mother with my secret knowledge, and she was hurt and astonished and insisted that if she paid more attention to the other two, it was because they needed her more than I did, that I was always more emotionally independent.

Despite this apparent emotional independence, the young Betty suffered 'wild nightmares and nervous imaginings in the dark'. She left home early, marrying 'the first grown man who came to court, who could actually prove he was financially solvent.' In short order, she left her husband but not before bearing three children. 'He was a bit of a compulsive collector of intact hymens. He couldn't seem to stop after we got married. He finally collected one too many.'

Three more marriages and five more children followed in the next two decades. Barbara Ellen was a seventh among them, born just before Betty moved to Canada in 1966, 'six kids in tow,' and her third marriage on the verge of breaking up. They lived in Kirkland Lake, Ontario. Her husband, a college instructor, was an emotionally distant workaholic who also drank. 'I didn't like John when he drank,' she writes. 'He had a tendency to get impossibly self-righteous and accusatory. So I found myself avoiding the same social situations I had originally reached out for. And my depression deepened... I began to look at John and wonder who he actually was... I thought that first winter in Kirkland Lake would never end and that spring would never come. Actually, spring never did come... I think the two most frustrated people in that non-existent spring were me and the baby, Barbara Ellen.'

Betty found a way out of that relationship with her husband by falling in love with his department head at the college and relocating with him to British Columbia. It was mostly here that Barbara Ellen grew up, although there were moves back-and-forth between Eastern and Western Canada and between the United States and Canada.

Betty's fourth marriage also failed, but over the years she found a truer sense of herself as a person, as a woman and as an activist.

Barbara Ellen was a sensitive child with health problems. At the age of four, she began to have vomiting spells that nobody seemed able to diagnose. These bouts recurred intermittently over the years, and Betty feels now they related to the stresses in her daughter's life. As a young adult, Barbara became addicted to narcotic painkillers and tranquilisers that she would inject into her body. Right up to the time of her diagnosis with breast cancer, she was fighting her addiction to drugs with no experience of stability. She was unable to establish an intimate, ongoing relationship with a man; she went from one relationship to another. Julian was born when Barbara Ellen was 25, but when she married shortly afterwards it was not to her child's father. 'That marriage didn't last long', says Betty. 'Martin was not able to cope with being married and having a little stepson.'

Barbara was highly intelligent, sensitive and creative. A dancer, at one point she operated a ballet school for children. She was taking care of Julian and doing teaching of dance classes in Vancouver when she discovered her cancer.

'She told me she had had this mammogram and they just wanted to do a mastectomy. She wasn't willing to accept that. Barbara had a keen intellect. She researched all the material on the kind of cancer she had and investigated the treatment outcomes among her age group in the US and Canada. She didn't like the way it looked. 'I'm not going to go through all that,' she said. 'I don't want to be sick. I don't want to be mutilated. I don't want all this chemo stuff. I'm going to treat it holistically and do the best I can with it.' She asked that John and I support decision and not try to interfere.'

'How was that for you?'

'It was horrible. Immediately I wanted to do something. I tried to pressure her to look at some other options, and then she was just very, very angry and adamant and yelled at me - she never yelled at me before. She was angry with me the whole last, I would say, six months of her life. Before, she wouldn't stay mad; when she was angry with me, she would just say 'okay mom, you want to think that, you think that,' and she would slam her door or something, but that would be it.'

'That's not exactly an expression of anger - mostly of defeat and frustration.'

'She was always hurt by me for some reason, and I don't know why. I think I was a terrible parent for this child. My personality was hurtful to her.'

'You're full of tears here. Are you still feeling guilty about it?'

'Maybe not so much guilt as a feeling that why couldn't they have given her to someone else who could've dealt with her. She was an extraordinary child in her sensitivity to the world, her understanding of the world, in her gentleness with the world.'

'Gentleness... what was she like as a child?'

'She was very precocious. Wherever I took her, people were impressed with her demeanour and level of - I don't want to say that she acted adult - but at her level of comprehension of the adult world.'

'How about emotionally?'

'Emotionally? She was a very loving and affectionate child. She was quite gentle and was always very loved by everyone, was always the teacher's pet. Other kids don't seem to resent it, though.'

Do you have any sense at all that anybody ever tried to abuse her?'

'There was one incident. We had been in Louisiana visiting my mother and sister. My sister had these four boys. One boy was a year older than Barbara and bigger. Barbara would've been about 12. She didn't tell me about this. It wasn't until after we got back to California that she told Margaret, her sister. Margaret came and told me that this cousin tried to get on top of Barbara. They were the only two at home. Barbara was very angry about it. I remember asking Margaret, 'Why didn't she come tell me?' and she said, 'She thought because Doris is your sister that it would cause a big ruckus between you two.'

Betty and I then talked about Barbara's illness and death. At the time Barbara was diagnosed with cancer, Betty was running in a provincial election for the Green Party. She resigned her candidacy to spend time with her ailing daughter. I asked if she had found that difficult.

‘It wasn’t that hard. My feeling was that we needed each other. But there was something in my personality that Barbara always found irritating. My voice was too loud for her, my actions too flamboyant. I was too much for her more delicate constitution - that’s the only way I can describe it. I’m too loud and too definite in my opinions and too aggressive in my actions. She had the opposite personality of liking to think about things and being quiet and trying to have a more holistic view of other people’s personalities.’

‘It sounds like she thought you were more judgmental than she wanted you to be.’

‘She always accused me of being judgmental. I stayed awhile and she told me to go. She would always tell me when she was tired of me and she needed to rest because she found me tiring.’

‘This is in the last months?’

‘Yes.’

‘Why do you think that is? You can’t be tiring. There’s no such thing as a tiring person.’

‘My personality would tire her after a while – it was too intense.’

‘When does one get tired?’

‘When you’ve been working. So you think it was work for her to be with me.’

‘She had to work too hard around you.’

‘Aha...’

‘Now you’re wondering why I’m saying that. You’d be very unusual to be open to hearing this, but your whole life has been a search for truth. I know I understand that. Look, Barbara came along in your life when there was just no stability at all.’

‘That’s right.’

‘You were going through the end stages of your relationship with John when you got pregnant with her, and you felt totally alone. You didn’t realise that this guy didn’t feel partnered and you began to realise that while this guy was interesting intellectually, emotionally you were quite alone. Your way of leaving the relationship was to get involved with Wally. Then you make this flight to Western Canada with the kids in tow. What ends up happening is that John gets custody of everybody except Barbara Ellen. She had an awfully huge void to fill in your life all of a sudden, right from the beginning of her life.’

‘The nature of stress is not always the usual stuff that people think of. It’s not the external stress of war or money loss or somebody dying. It is actually the internal stress of having to adjust oneself to somebody else. Cancer and ALS and MS and rheumatoid arthritis and all these other conditions, it seems to me, happen to people who have had a poor sense of themselves as independent persons. On the emotional level, that is - they can be highly accomplished in the arts or intellectually - but on an emotional differentiated sense of self. They live in reaction to others without ever really sensing who they themselves are.’

‘Barbara’s going from one man to the other shows she hadn’t enough of a sense of self to hold on to. As soon as one relationship is over, she had to get into another in order to feel okay about herself. The addictions enter into this as well.’

‘She comes along in your life when you are particularly emotionally needy and exhausted. I think her precocious intellectual development is what happens to bright and sensitive kids when the emotional environment isn’t able to hold them enough; they develop this very powerful intellect that holds them instead. Hence their intellectual maturity and their ability to relate to adults. People would tell me as a child how mature I was. I always thought I was, because in that mode you can seem highly mature. But then when I look at myself emotionally I’ve been very immature. I’m 58 now and still trying to grow up.’

‘This is very interesting.’

‘What doesn’t develop in one area will overdevelop in another, if the kid has the brains for it. Barbara develops a huge intellect in order to feel comfortable. I believe that’s because you were not able to give her the emotional sustenance that she needed when she was small.’

‘I don’t think so either.’

‘When the parent can’t put in the work to maintain the relationship, then the child has to. She does so by being a good girl. She does it by being precocious, by being intellectually mature. When she reaches the age of abstract thought, around age 13 or 14, when these connections in the brain actually happen, all of a sudden she becomes your intellectual sounding board. The relationship is based not on her needs but more on yours. With the incident of that boy trying to climb on her, she protects you from her emotional pain but not telling you. She doesn’t let you know about it. She is taking care of you.’

‘She wants to keep peace in the family. That’s not the child’s role. The child’s role is to go to her mother and say ‘this bastard tried to climb on top of me! To hell with whether there is peace or not’. I know that’s what you would’ve wanted to do. None of this is deliberate. It all goes back to your own experience as a child.’

‘I’ve had very similar interactions with my eldest son as you describe with Barbara. He said to me at one point, ‘Dad. I don’t know where you end and I begin.’ That’s just how it is. I’ve always said that I’m not worried my kids will be angry with me. I’m worried they won’t be angry enough.’

‘What you were finally seeing in Barbara’s last six months of life is that she was beginning to set boundaries. She was saying no, and the anger that she had repressed was coming out.’

‘Right...’

‘This is how I perceive it. The people that I see with cancers and all these conditions have difficulty saying no and expressing anger. They tend to repress their anger or, at the very best, express it sarcastically, but never directly. It all comes from the early need to build the relationship with the parent, to work at the relationship.’

‘I think for Barbara it was a lot of work to maintain the relationship with you. I recall just very gingerly raising the issue. She indicated to me that there was something going on, but she also didn’t want to talk very much. She was very much pulled into herself - I was a total stranger to her. She wasn’t about to open up to me.’

'It wasn't easy for her to open up. In the last months she would actually ask me to come and smoke a joint with her, so then we could be relaxed and talk,' Betty says.

'How was that?'

'It was good, because she would talk about herself. She was say 'I feel that I don't know what cancer is, but it's here and it seems like it's been visited on me.' She said, 'I've invited the cancer into my body.' I remember being horrified and saying 'Barbara, I don't understand that.' She said, 'well, it's because I experienced it as part of my own life and that you're a part of this to, Mom. You have your own part of my cancer.'

'You know something else, Gabor – she saw somebody the night before she died. She said there was a man who'd come to take her and she told him she wasn't ready. The next night, she said to me, 'that man - I want him to come'. I said 'what man? Do you want me to call the doctor?' She said 'no, the man who came for me and I told him I wasn't ready.' She said that she was ready now.

'I had told her a few hours before that if she was tired of being sick she didn't have to hold on any longer. I'd said, 'okay', and it was then she told me about the man. She told me that she was ready for him and she died. Have you ever read any of the Kubler-Ross stuff? You know where she says about escorts... people who come for us as we die. It was so weird. It really made the hair stand up on the back of my neck.'

'Why is that weird for you?'

'Well, do you mean there really is an angel of death?'

'Does it have to be like that? The mind has an experience, and we translate it into an image. There is a deeper sense of something that's happening, but the mind can only experience it in terms of thoughts and images.'

Betty had one final question: 'Why can't parents see their children's pain?'

'I've had to ask myself the same thing. It's because we haven't seen our own. When I read your book, Clayoquot, I saw the evidence in your writing that you hadn't recognised your own pain yet. It would not be possible for you to clearly see Barbara's either.

'If you think of it only in terms of you and Barbara, you're going to feel more guilt - you may accuse yourself of things that wouldn't be fair to you. The fact is, you are the product of a certain upbringing and a certain kind of life. Your life has always been about trying to find yourself and about trying to find truth in the world. It's been a real struggle. It's amazing what you've done, coming from the background that you described. Still, are you sure you want to hear this?'

'Please continue.'

'You dedicate Clayoquot to Barbara Ellen but also to your 'wonderful mother'. Your mother may well have been wonderful, but when you write this, you are not fully aware of how angry you are with your own mother and how hurt you were by her. 'My mother was warm and loving, but I always knew she favoured my brother and sister. She was so full of love that some of it slopped over to me'. How does that actually feel to a child - whose perspective is this?'

'I never felt unloved.'

'Of course you didn't feel unloved, and I'm not saying your mother didn't love you. But partially you didn't feel unloved because you shut off your pain around it. You write, 'After I grew up I once confronted my mother with my secret knowledge, and she was hurt and astonished and insisted that if she paid more attention to the other two, it was because they needed her more than I did, that I was always more emotionally independent'. That was your particular ruse to make it look like you are emotionally independent, to protect your mother and avoid your hurt feelings. That was suppressing your own pain.

'Although I always knew she favoured my brother and sister, she was so full of love some of it slopped over onto me' is also the perspective of an adult trying to distance herself from the emotional reality of the experience. The child's perspective would be different. How did it actually feel?'

'I know I used to resent the attention paid to my little sister because she would hold her breath and turn blue. Later, she studied to be a nurse practitioner, to get a nursing degree, and she had four children. She was an addict and alcoholic and she died before she was 50 from an overdose. My parents tried with her... my mother tried desperately with her.'

'You're so quick to jump to your parents' defence.'

'That's because I'm a parent.'

'I think it's because you're defending yourself against your own pain in your relationship with your parents. You had nightmares.'

'Everybody would have nightmares if they drank all the iced tea I did...'

'Nightmares are about deepest anxieties. A kid is afraid of monsters under the bed. You turn the light on and show him that there are no monsters, and the next minute he is afraid of the monster again. What is he actually afraid of? He's afraid of not being protected, about not being connected enough. Maybe there's something monster-ish in the parent... Maybe the parent is angry so the kid is really scared. The kid has all this fear, so his mind will create the image of a monster.'

'The nightmares I had were about my father. I detested him. Not too long ago, I was talking with my brother, who was very much brow-beaten by my father. He became an aeronautical engineer in spite of all of it; although he himself had been a lifelong alcoholic, he is a functional one, and actually excels in his field. Not long ago he said, 'You know, Betty I always admired you when we were kids because you weren't afraid to stand up to Dad.' That isn't true - I was petrified of Daddy, but I would offer some resistance. To my brother, in his mind. I was a freedom fighter because he would never say a single word to my father. My father called him a sissy because he just studied all the time.'

'Another reason you had nightmares about him is that you couldn't talk to your mom about any of those feelings.'

'What was I going to tell mom - I hate Daddy and I don't know what in the world you're doing with him.'

'No, just mom, I hate Daddy.'

'It wouldn't have washed. The Bible says you honour your mother and father.'

'I'm not blaming the mother because she is in this relationship - she has her own history. She can't very well fight and upset the apple cart. But for the child, the bigger wound is the experience with the mother. You come from the mother's

body and you relate to the mother. The mother is the universe for you. It's the universe that lets us down. When the father comes along as an abusive, threatening figure, the universe protects us, or the universe doesn't protect us.

'Now, I'm not saying it's the mother's fault. It has to do with the position of women in society and the relationships people get into. I'm talking only about the child's experience. The child doesn't know it, since you can't miss what you're not familiar with, but the child is actually experiencing abandonment by the mom. When you say, 'That wouldn't have washed,' what you're really saying is your mother had no way of hearing your root feelings. We don't tend to think of that as wounding, but it is a deeper wound than anything else.

'There is a wonderful feminist book by Dorothy Dinnerstein, *The Mermaid and the Minotaur*. It discusses how the exclusive role that women have in early child raising distorts child development. When the woman is married to an immature man, she's also a mother to a husband, so she hasn't got the openness and the energy for her kids. So your real rival for your mother affections wasn't your sister, it was your dad.'

'It's so odd because all three of us, before my sister died, were talking one day about my father. The animosity that I feel for my father is nothing compared with what my sister and brother felt. They both hated my father so much. We were talking about my father, and my mother came into the room and she said, 'You know when you kids talk about your father, I've always felt angry with you, because your father was a good man'. She also said 'I don't think I paid enough attention to any of you. If I had it to do over again, I would pay more attention to all of you and less to Daddy.'

'Perhaps. But she may not realise that he got the attention that he demanded. Had he had less, he would've made her suffer for it'.

It was Barbara Ellen and her aunt who died of an overdose and her alcoholic uncle and her brave mother, Betty, and all Betty's children who, to one degree or another, suffered for the demanding immaturity of Betty's father and for the lack of assertiveness by her mother. And these parents, too, were suffering and carrying the burden of generations. There is no one to blame, but there are generations who had lived to bear a part in the genesis of Barbara Ellen's breast cancer.

Mate, G., (2019), *When the Body Says No: The Cost of Hidden Stress*, Penguin Random Press, UK