

INGE WENDE



*Life Between  
Fear and Hope*

My personal experience with leukemia

Inge Wende

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with leukemia

*Leben*   
&  
*Hoffnung* e.V.  
Leukämiehilfe • Missionswerk



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The English edition  
is dedicated to

*Becki*

(Rebecca Joyce Crain).

**M**y name is Inge Wende. My way has been a dreadful one, which many don't survive. But I faced it differently from the way most do, because I have a foundation in my life which bears me up.

**T**his booklet could have borne the title "Highlights Write their Own Stories" because in writing it, I had to think of many highlights in my life, both positive and negative. Certainly it was easier to accept the positive highlights than to cope with the difficult negative situations.

**O**n the eve of Good Friday 1988 I lay in the university clinic in Giessen, Germany. Early that morning the doctor had come into my room to break the news that I had a very aggressive form of leukemia. No! That can't be true!?! Everything went through my head in a confused rush.

Surely my life still lay ahead of me!  
Our children still needed me!

**M**y heart pounded; the clock went on ticking; I pinched myself to make sure that this was not just a bad dream! The doctor was still standing by my bed. I asked him some questions which, of course, no one could answer: "Do I have a chance – will I live?" My fear and distress made it hard to breathe. As a former nurse, I knew what this diagnosis meant. But what exactly was to come, I could not at that time imagine. We made an appointment for the same evening to talk it over together with my husband. Meanwhile, both of my roommates had discretely slipped out of the room, leaving me all alone. – Was I really alone? –

After I had calmed down a little, my thoughts reeled on the things that lay ahead of me.

Questions ran through my head: "What will my husband say, our parents, brothers and sisters, our friends, our children?" Especially I thought about our children who had just witnessed what had happened to our friend, Jamila, only four months before. Jamila was dead now! She died on the eve of First Advent Sunday. She too had leukemia. The problem in her case had been that she came from Syria, where she had been unable to receive treatment. Because she had no health insurance in Germany, the entire treatment had to be paid for privately. Together with family and friends, we stayed by Jamila's side for nine long months. We publicized, through several newspapers, her story: her leukemia,

her five small children and the high cost of treatment. Our children – at that time nine and fourteen – gave their savings, told those with whom they had contact about Jamila and her children; and that they wanted to help collect money, so that she could be treated in Germany and be healthy again. In this way we collected 200,000 DM (about \$ 100,000).

**J**amila didn't make it! She died on the eve of First Advent Sunday 1987, two weeks after her bone marrow transplant. All the struggling, trembling and hoping had been for nothing. – And now, four months later, we found ourselves in the same situation!

**A**fter these scenes from Jamila's story had passed through my mind, I thought of our children; and I knew one thing: I would let them do anything to me; but a

bone marrow transplant? – never! Because our children had been so intimately involved in the death of Jamila, I didn't want to expose them to the fear of another failed transplant.

**W**hen a short time later my husband came, the first thing we did was to cry and to pray together. Was I really so alone now? Didn't I have a father in heaven who had promised to be with me every day? To never forsake me and to always be at my side? I had many years before entrusted God with my life. As a convinced Christian I had experienced many highs and lows. In the Bible it says, "I will guide thee with mine eyes ...." How good that his eyes saw me now here in the university clinic in Giessen. I was able in prayer to express all my tears, needs, fears, worries and questions – and let them go. We asked God together to take it all into his hands.

In the evening we had an enlightening, informative talk with the doctor. At the end of it, he gave us the following advice, "First, we're going to do some chemotherapy. It's got to be strong enough to kill the cancer. But in the process your hair will fall out. Better have a wig ready for when that happens – that may be important to you as a woman. Your fingernails can go through great changes and may even fall out. Those are completely normal side effects of the chemotherapy; there's no getting around them. – Talk about your illness. If you do so, it won't weigh on you so much. As of today, leukemia is a part of your life. We haven't much time left to get the chemotherapy started. – Time is not on your side!" We told the doctor we would agree to anything except a bone marrow transplant. He too had known both Jamila and our children, and understood our

unwillingness to risk another transplant. "No matter what we do – as of now, what you have to face will be very hard. You have to fight!"

**W**e explained to the doctor the place that God and Jesus Christ have in our life and family, and that for us God himself is the great physician.

**W**e were allowed to go home for three days to get ready for the next two hundred. Our children would need a new home during this time, and that had to be arranged. My husband's employer agreed to give him the time off. During these three days, I thought a lot about my past and about the future. What happens if I don't survive? If I die, I'll stand before God and have to give an account of how I spent my thirty-seven years. It became my great desire and

need to ask forgiveness of the people I had wronged – and to get things straightened out with those who had problems with me. The important thing for me, was to be clean before God and man.

**A**t the end of those three days, the chemotherapy started. Fifty bouts were planned. These had to be aggressive enough to instantly annihilate the cancer cells in the blood and bone marrow. And they were the prerequisite for further treatment. Side effects of chemotherapy included severe damage to the mouth's mucous membrane. My mouth had to be disinfected with cotton swabs and solutions several times a day. The open wounds hurt so much, that I was nearly mad with pain.

**H**ow thankful I was in these moments, as my husband assured me again and again how much he loved me, and that my children stood by me.

**O**ur ten-year-old, Tobias, said, "We didn't love you because you had beautiful hair – We love you just as much without hair. We love you because you're our mama!" Fifteen-year-old Matthias sent the message: "Papa, tell Mama: I'm fighting with her!"

**H**ow cheering it is to know that family, parents and friends fight with you! How good, when you experience that the confidence you placed in them is not disappointed! Sympathetic greetings came in from around the country and abroad. A Christian choir visited me, and sang songs which comforted me.

*"But the Lord is still greater,  
Greater than I can conceive!  
Of the whole universe the creator,  
Everything 's subject to HIM."*

**A**t those times, when I thought that my strength was at an end and my courage was gone, I heard, as though floating into my room from the hall: *"But the Lord is still greater...!"*

**T**he fifty bouts of chemotherapy went on endlessly. The side effects were severe: high fever, mouth made raw, the lining of stomach and intestines destroyed, a lot of nausea, vomiting and pain throughout my body. I fluctuated ceaselessly between dejection and weakness. But in all these changes of emotion which washed over me, I experienced over and over that God himself stood by me; he gave me new courage, as well as comfort and joy.

**A**fter the fifty rounds of chemotherapy, my bone marrow was analyzed again. The findings were very encouraging. At the moment, no cancer cells were showing up. While there would be no need of a bone marrow transplant, the doctor explained to us that a part of the planned therapy entailed removing some of my bone marrow.

**T**his would be done at the university clinic in Heidelberg. There, under anaesthetic, half of my bone marrow was removed. This can only be done when the bone marrow is absolutely free of cancer cells. Then, outside the body, my bone marrow was treated with chemotherapy, and frozen. This could later be used for a transplant, if necessary.<sup>1</sup>

<sup>1</sup> Note: there are various forms of leukemia. Consequently, methods of treatment vary. In my case, my own bone marrow was available, so that I did not need a donor.

One special situation we experienced was meeting ten medical students in my room at the clinic in Heidelberg. They were to ask questions and form a diagnosis of my case. When the questions and answers were finished and the diagnosis arrived at, my husband asked them: "When you're all doctors later, how will you break the news of such a bad diagnosis to your patients? What will you say then? You're not giving them enough, if you send them out into blank hopelessness with only a diagnosis of that kind. What help do you offer – not medically, but humanly?" – No answer! Long silence!!!

Now we were able to tell how we had been able to cope with this bad news, where we found help, and what our foundation was. Every human being, who is faced

with such a diagnosis, always asks himself the question: "Was that it? Why did I live? What happens to me if I die now?"

In order to be able to answer this question, I need a foundation, which bears me up even in such times of crisis – the Bible – God himself is the foundation; the anchor which gives a firm hold:

*"For God so loved the world, that he gave his only begotten son, that whosoever believeth in him should not perish, but have everlasting life."*

*John 3 : 16*

*"I am the way, the truth, and the life: no man cometh unto the father, but by me."*

*John 14 : 6*

**T**hese statements mean that I have access to God through Jesus Christ. I need forgiveness of sins. If I can get this, I become a child of God.

From then on I have a father in heaven I can rely on; who will take care of me, even in such times of crisis – in fact, especially at those times. And when I die, I know that I will be with him in heaven.

**A**fter the time in Heidelberg, I had to go back to the clinic in Giessen for even more intensive chemotherapy treatments. “More intensive” meant 21 more treatments, each one 19 times as strong as the ones I had had before! During this time, unbearable nausea, pain, and vomiting were my constant companions. Words like “Hang on, it’ll get better” sounded so hollow and empty – so meaningless!

**B**ut I found that God had his protecting hand over me, and that in my need, I was able to pray. After some weeks I was released

from the clinic and was considered "healed". In spite of this, a few months later, I was caught in an inner crisis. Because of a light throat infection, my blood count was suddenly off. A bone marrow sample had to be taken to find out if a leukemia relapse had taken place. After the test, we drove home and waited for the professor to call us later that day with the results. The hours of waiting began. I cried in my heart to God!!! – Had all the anxiousness, hoping, and struggling been in vain?!? Could the leukemia really have broken out in my body again?!? Up till now, everything had looked so good. Was it to begin all over again – that time of pain, need, nausea, vomiting, helplessness, and my children's fear that they might lose their mother?

I felt so alone. I couldn't come to grips with it all any more. Despe-

rately, I tried to pray, and realized that I had no more peace in my heart. It occurred to me that God could resolve the situation for me by having the doctor call and say, „Mrs. Wende, all the excitement was for nothing; the machines that give the blood count give misleading results sometimes. Your bone marrow is free of cancer cells. You’re perfectly fine!”

**B**ut unfortunately this call didn’t come. I endured real agonies for fear I might have leukemia again. Endless waiting, waiting, waiting...! Many hours went by until finally, at nine o’clock that evening, the telephone rang. My sister-in-law called me to the phone with the words: “It’s the doctor from the clinic for you.” –

**I**n the same moment, I was reminded of these words from the Bible, from Isaiah 43 : 1-3 :

*"Fear not: for I have redeemed thee, I have called thee by thy name; thou art mine.*

*When thou passest through the waters,  
I will be with thee; and through the rivers,  
they shall not overflow thee!*

*When thou walkest through the fire, thou  
shalt not be burned; neither shall the flame  
kindle upon thee. For I am the LORD, thy  
God!"*

**I**mmediately I experienced an indescribable peace in my heart. It was as though scales had fallen from my eyes and I could see! I'll never die because of leukemia or because of a bone marrow transplant, or any other disease or drastic medical procedure; I'll die when God wants me to! I knew at once: my father in heaven will take the responsibility for my husband, for my children, and for me, too, no matter what news comes now. My

heart was suddenly so happy! I could have embraced the whole world!

The doctor regretted to inform me that cancer cells had indeed been again found in my bone marrow, and that therefore a bone marrow transplant would now be necessary. It sounds unbelievable, but all this was for me, in that moment, no longer important. Only one thing mattered – I felt again deep security and peace in God.

The bone marrow transplant, which had been unthinkable for me nine months before, was now the next order of business. I was very quickly given a bed in the clinic. I had to go for a week to the university clinic in Heidelberg, to be prepared for it all. On Christmas Eve my husband was allowed to bring

me home for two days. This was Christmas 1988. I wasn't afraid of what was to come. Continually, the words were with me:

*„Fear not: for I have redeemed thee!“*

and: *„When thou passest through the waters, I will be with thee!“* and:

*„When thou walkest through the fire, thou shalt not be burned. For I am the Lord, thy God!“*

**T**hat Christmas we celebrated very appreciatively and happily with one another. Would it be the last festive time together? The Saviour, the rescuer, my redeemer is born. What a privilege to belong to this redeemer. Naturally, and with light hearts, we sang: *“Christ, the Saviour is here....”*

**T**he farewell on the second day of Christmas brought pain and tears in our house, but the peace of God remained. The preparations for

the bone marrow transplant were to start off with repeated exposures of the whole body to radiation: twenty minutes each, three times a day, for four days. At this point, I already knew that these ultra-hard treatments with such sustained duration could kill my body. But I didn't have any other chance. – Following this, I was subjected to four days of the high-dosage chemotherapy (again 19 times as high as the original level). This was done five times a day. Then came a one-day break before getting the bone marrow transplant on the 5th of January, 1989. My own bone marrow, frozen earlier, was used.

The next weeks brought a lot of suffering. At first, my days consisted of fever and great pain, which were the result of the radiation treatments.

Morphine could only relieve the pain for short periods. But the peace in my heart remained in spite of all

bodily suffering. I was thankful to my husband's co-workers as they sang to me over the phone: *Lord, because thy strong hand holds me fast, I quietly trust....*"

Could I really, truly still be trusting? – In spite of being burnt by the radiation? To God's glory I'm able to say that at no time then did I quarrel with God. The peace remained!

**T**he day of the bone marrow transplant was the eleventh birthday of our son, Tobias. Since that time, we celebrate this day together. Every year it is a high point in our life. Since then, we have spent many Christmases together, too; and always on Christmas Eve we sing: *Christ the Saviour is here!* – our saviour, – my personal saviour. Once again I think back on those bygone years. I remember praying, on the eve of Good Friday, 1988, when I first heard the diagnosis, leukemia, "Lord Jesus

Christ, if you still give me years to live, (though I know the chances of that are poor), I will pass on the story of what you have done for me.” – Meanwhile many years have passed, in which cancer-sufferers have asked us for help. We have seen more and more clearly that our task is to be of help to the sick and to their families, and to stick by them, to help keep marriages and families from being broken by this sickness. My husband once said, “When you love the sick person, you suffer till you break down, too. The family has to stay intact.”

**T**hrough my previous experience as a nurse, I learned that many people couldn't cope with the suffering of a loved one and that the diagnosis "*cancer*" had the same effect on them as a contagious disease. Here my husband and I would like to offer help to the sufferer and family members – even to the last hour!



Here my frozen bone marrow  
is being thawed.



After the diseased bone marrow had been completely destroyed by very strong chemo- and radiotherapy,



the healthy bone marrow could be put back into the body through a vein.

With great thankfulness we've been able to do this work for some years now. Heights and depths are still my companions today, but I'm thankful from the bottom of my heart for every day of life God gives me.

As I wrote my life story in 1996, many years of physical highs and lows lay behind me. With every low, I have faced the question afresh, whether the feared relapse had come. Again and again we experienced in these special and difficult times God's gracious working and protection. I never would have thought that from my own experience could come my life's task of personally encountering other leukemia sufferers in no-way-out situations.

In October 1998, we founded with friends, who had long been encouraging us to do so, "Leben und Hoffnung" (Life and Hope Mission) – assistance for leukemia sufferers.

Leben   
&  
Hoffnung e.V.

Leukämiehilfe • Missionswerk

**T**oday, I can keep house, with reduced strength. Increasingly I see it as my task to encourage sufferers of leukemia and to support them with God's word. I am very thankful that our whole family supports us in this task. The "red thread" of God's love has remained visible from the time I first became ill with leukemia till today.

**T**his booklet is dedicated to people in life-threatening crisis situations.

**I**t is also an expression of my gratitude to my husband, Rainer, my children, Matthias and Tobias, our parents, brothers and sisters, our church, our friends, and those who pray for us. Thank you for all your love, support,

friendship, and help throughout the many months.

**I**would also like to thank the doctors and nurses at the clinics in Diez, Giessen, and Heidelberg for all medical and human help.

**B**ut my greatest thanks are to my personal saviour, Jesus Christ.



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We thank all those who assisted us in conceiving and translating the English edition.

This brochure is available in the following languages:

- German
- Russian
- English
- French
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Also available:  
a cassette containing words of comfort and consolation for people in difficult situations „Be of good cheer - you are mine“  
(in German only !)

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