

# e l e a n

Edited by  
Nunzia Invernizzi  
Giuliana Parodi  
Bernard Worthington



r Tolerance and Ability  
Eleanor Worthington Prize  
second year



I have chosen to symbolically represent one of the many encounters of Eleanor's with a creature which is "different," but made of the same vitality, the same mixture of signs, as a trace of a single plan of infinite love.  
An encounter without prejudices, a model of tolerance and the capacity for a deep relationship.

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**Eleanor  
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**Opera implemented with  
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The Editorial Board has taken care  
of this book in memory of Eleanor  
written by many hands.  
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## THE FUNERAL

Bernard Worthington  
Dedication by Martin Worthington

This is the story of a disabled young woman told by the many people who have been close to her: parents, relatives, friends, teachers, doctors and nurses.

From their various accounts there emerges a young person entirely capable, despite her condition, of social interaction. Her unusual, though complex, upbringing aroused many emotional reactions which brought those around her to reflect deeply on life.

This book is edited by Nunzia Invernizzi, Giuliana Parodi and Bernard Worthington, dearest friend and parents of Eleanor, as second year of the prize “Tolerance and Abilities” in memory of Eleanor.

The covers of the volume have been designed by Maddalena Fabbris and Mirko Boinaga of the final year in Publishing Graphics of the Istituto Statale d’Arte of Urbino.

# 01

REFLECTIONS

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# PROFILE

**Eleanor Worthington was born in York, Great Britain, on 9 January 1982 of an Italian mother and a British father. She had an elder brother, Martin, born in 1980. Her family was at that time living in Genoa where she was taken shortly after her birth. Throughout her early life the family moved frequently between Britain and Italy and she was a native speaker of both languages. In childhood she developed severe epilepsy on account of brain lesions caused by a rare congenital syndrome. The fits were never fully controlled and at times scarcely controlled at all with twenty fits or more a day. Her behaviour reached points of extreme difficulty which, among many consequences, made a conventional education impossible, though she attended ordinary schools with a remedial teacher. Beneath her disabilities she was of high intelligence. It was observed by all those who knew her that she also had a forceful and engaging personality. In 2003 her disabilities rapidly worsened and she spent several weeks in the intensive care unit of Urbino hospital. She was now in effect quadriplegic, movement below the neck being limited to weak control of one lower arm. She was fed through a tube and could no longer speak. Some feel that in this period, since her behaviour disorders had been eliminated, she was herself happier. In 2008 she contracted influenza. This turned into**

**pneumonia and on January 12, in the presence of all her immediate family she died. Her ashes are interred in England close to those of her paternal grandfather.**



(Eleanor and Daddy in Earby)

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# AN ATTEMPT TO UNDERSTAND/ THE MOTHER

# 1—

I'm the mother of Eleanor Worthington who died on the 12th of January 2008, aged 26. Eleanor was an extraordinary person and I've experienced the fact that she was given to Bernard and me with great amazement and reverence. We wanted the very best for her and we were beside her in her difficult journey in all the ways we could. In this we were helped and supported by many dear friends who created a security fence for Eleanor and us in a way that we felt loved and supported and never (or almost never) rejected or discouraged. For many years I was overwhelmed by the effects and difficulties which daily life with Eleanor brought. Only in the last five years, when all was much slower, was I able to reflect on Eleanor as an extraordinary person. I remember the sacred phrase : Mary "held all these things in her heart." I seemed to be listening and holding this extraordinary person who happened to be given to me. In those five years Eleanor could have limited herself to a struggle to remain alive without giving herself up to the total change that her physical condition was imposing. But instead she grew too and went forward in a process of interior maturation and emotional growth.

She related to the persons who loved her in a more intense and profound manner. She reflected and interiorized experiences. She learned how to give space to others, to lend and to give. She demonstrated a desire to live with much joy and participation in what went on around her, giving a welcome to friends, enjoying gifts, being sad if someone was ill or as a result of bad news even though it did not directly affect her. She had a very deep friendship with the conscientious objector who looked after her, the young man who decided to replace military service with community work. She suffered severe physical pain when it became necessary to put the feeding tube back and when she had toothache. She learned how to breathe again six months after the tracheotomy performed by Dr. Martinelli. She showed in an extraordinary way how any experience, even the most difficult, can be lived totally with participation in the life going on around, without letting herself be excluded by her physical disabilities. Only those

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## Mary held all these things in her heart.

people who hadn't met her could say that when she died she stopped suffering. Those who knew her remember her as a great example of a love for life. I've always thought that she would stay with us as long as she wanted. And the great effort of those five years was to make her want to stay with us. I don't

know if Eleanor knew she was so very ill. We knew.

She seemed to be on the crest of a wave which went away and away, so far away that perhaps it never finished. Then the wave fell, suddenly, in four days.

In those last five years the mysterious aspect of Eleanor increased. Like Martin, we called her the "Little Buddha": she released force, real physical strength and was at the centre of a world of great creativity and oneness where we all worked with the aim of making her happy and wanting to stay with us and keeping her with us.

Now that she couldn't use words or gestures, Nunzia opened a channel of expression based

completely on creativity, and following this strong impulse the entire household took up the cause and those that came joined in the party. In the home there was always something lively going on: laughter, projects, jokes, water and pastel colouring, collages, origami, felt cutting, pipes, piano playing, ravioli, jam tarts, recitations and dressing up.

She was attentive to all this: she looked, laughed, stayed with us or nodded off. There were difficult moments too, the sudden fevers with high temperatures which lasted a day and then left her, leaving us exhausted. There was the tube that came out, and always the thought that it could have been avoided. There was the anxiety of feeding her well and of managing to concentrate in liquid form all the required nutrients, the fear of her catching a cold, or coughing, or catching bronchitis. But these were little things: our real energy went into the total project that she should want to stay here. Now that I think of her only through recollections I notice it's easier for me to talk about the final five years and when she was a young child because it was easier in those periods to stay close to her. But there's a total continuity in life, in the desire to grow, to transform oneself, to go forward, transcend limits that seem impassable. Perhaps we could say that that transformation is the human condition, which isn't so extraordinary a fact as to be worth writing about. Eleanor had a very difficult start which affected her whole life and we'll never know if the last five years were the most difficult for her. She could have given up, just lived on in an attempt to survive such a difficult life. Instead,

she went further: she loved, sought means of expression, wanted to expand her world, to accept the challenge, and she wanted to affirm her rights. She had a sense of the amazing and the wonderful which left her able to approach unconfined worlds and transcend daily concerns. She was able to capture the disruptive elements of life that offered an exit from life's patterns. There was the possibility of a break, of going further. In the last five years it was easier for

us to notice these things because the vortex of continuous movement and the epileptic attacks had stopped and we could observe and reflect without the worry that she'd hit her head on the ground and without the continual vigilance necessary to avoid catastrophic situations. But all her life she showed the same determination not to accept her limits, to go further, developing her affections and acquaintances, and with courage.

I write this account for many reasons:

in writing it I can think about her for all the time and I can stay with her. Now that all has passed I can reflect in silence, calmly, without having to be concerned about things.

And it gives me pleasure to let others know the story of that extraordinary person, as far as I can recount it, because I think it's a story that gives strength and a sense of transformation.

I'd like to think that the story can speak of what many experience and that for those just reading a story similar to theirs it can give encouragement and strength.

I'd like to think that the story could be

a point of reflection, and create other personal

stories that always move in the direction of growth, change and opening up. I think – I hope – the many young people who loved her and whom she loved, get strength from this account in difficult moments when they seem to see no end to them. Bernard and I made a key choice from the start: to share all aspects of our life with her and ask the same of those we met in England and Italy. We went together to the Conad supermarket, to Bar Basili in Urbino, the post office and on the planes and trains. She went to a normal state middle school (she was the first to go – now there are seven or eight. It's pleasing to think there's a wedge effect) She passed happy hours at the bingo of the VASIS, the parties at ANFFAS and the two big theatrical shows of Ulrike's with the rehearsals at the Posto delle Viole.



(Eleanor and the hot-air balloon)

## 2—

We had a lot of help at home: first very charming young girls – always English to keep up Eleanor's bilingual ability – then middle-aged, very capable ladies who wanted to spend a period in Italy. I think she had a happy life, in the total sense – one does what one can. She had travelled in the worlds of family and friends, in that of the school and in that of the therapists. She reacted to everything, and in everything, or in the much greater part of it, she found understanding and availability that allowed her to live a full life. People who have never found themselves in that kind of situation have, after that deep experience, developed a sensibility that is special and recognisable. At the elementary school of Montesoffio her classmates stayed near her during the play break like a flock of sheep. If she had an attack they came close and supported her, all spontaneously, without anyone having suggested it.

The big meeting, certainly for me, was at Mestre with Anna Dalmaso and Dr. Vitali who gave us a key to interpreting Eleanor's actions. The points we had extreme difficulty understanding and acting on were interpreted by them as expressions of unease and our task was to anticipate these situations: never to have a total confrontation, always have an exit route. These are the things which we as adults should be able to arrange. It required total trust in her intelligence and recognising that the problem wasn't on entering, but in exiting: she understood everything but lacked the means of expressing that understanding, so frustration came, with lack of self control, and the frustration at not finding exits. Her violent and aggressive temper was an experience that is certainly at times common to us all but she couldn't dominate it and find a channel of expression that was acceptable. A number of body exercises were used to exteriorize the sense of limits and of self control: playing inside a circle and coming out at a command; stamping a foot on the ground in rage, clutching a fist, shouting loud as an act of liberation. These were all attempts to find means of self control and expressions of unease that are acceptable when you begin to lose self control. Then there was making her recognise an autonomous, decisional objective in order to give her self-esteem, the sense of herself being the subject that knows and can assume responsibility. There was total trust in her ability to understand, read and write which had to be mediated to get round the difficulty with the exit channels; proposing complete processes to her which implied transformation, in the areas that interested her, in order to interiorise the idea of change and possible transformation, so as reach the great destination point

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– the departure point wasn't important. From flour to the bread, pizzas, desserts!

In Mestre she gave the very best of herself: she was attentive and spoke and replied to Dr Vitali, a very nice man. She showed all her skills: on one occasion she'd play basket ball, on another she did typing. They showed her a drawing of a merry man holding a foaming glass of Guinness and she wrote "Beer." It was followed by the usual way she expressed satisfaction or knew she'd done well: a little jump, a little roar, the stretching of the left arm down the body, and a crafty little facial expression. Another important meeting was with Doctor Morosini in Milan. She was an incredible person who was introduced by a friend. She was very old and smoked a pipe. When Bernard, Eleanor and I came in she briefly greeted us parents and started a conversation of equals with Eleanor who in that period had great difficulty expressing herself. It came out that she had a brother who was taller than her with brown eyes whom she loved very much and was living in England, and that she was living in Urbino. The lady gave us technical advice about the exercises we should make her do in gymnastics and in language. The advice that struck me above all was that of giving her the activity that amused her,

which gave her joy and freedom. She mentioned canoeing, riding and doing very entertaining, out of the ordinary things that gave satisfaction. She proposed other ways of finding a channel of expression and liberation for the deeper and more disruptive feelings, activities that for Eleanor were extreme, in order to take her outside the limits that her disabilities imposed. The contradictions present in each of us were much increased in Eleanor.

She was a person with an extremely gracious personality, very attentive to the nuances of and changes in the moods of people, and very involved in the feelings of joy and pain in others. She was a person with a happy temperament, always ready to meet people, do new things and experiment with food. In her there was a great tension between being and the desire to be, the attempt to reach "the fullness of existential fulfilment" as Father Adriano said. I don't know if it was a source of suffering but it was certainly a stimulus to go forward, to change oneself, to not accept what seemed an obvious limit and so impassable, and to reach what



(Eleanor and her mum)

Perhaps I understand better  
the attempt to realise  
“who I’d be if I could”

she desired with extraordinary courage and determination. She expressed this in her way of communicating, in concrete, straightforward things. She wouldn’t accept anyone doing her a wrong: the error had to be recognised and she was worthy of respect like everyone else. She wanted to grow a lot and considered status symbols very highly. Perhaps her taste for dramatic situations reflected her desire/attempt/effort to go further, to force a predetermined situation which could only stop her movement. We laughed at this little consumerist who wanted the latest trainers and the most colourful outfits. Perhaps I understand better the attempt to realise “who I’d be if I could” as Montobbio wrote, through symbols that would make her as important as the others, as big as the others. There were moments of great tranquillity, of deep concentration in which she expressed herself with serenity but with the usual vivacity and total involvement. In those moments she enjoyed friends, affections, daily actions, joking, parties and nice stories. And then there were the terrible moments, a great suffering for her and for us, in which she was very aggressive and attacked those of us who were close to her, or people who were unaware that they had done something which caused her annoyance. You understood that when this happened she herself was disturbed, that in the depths of the raptus remained the consciousness of it but she lacked the ability to control it, and this created about her a barrier of bewilderment and diffidence when in contact with people, contact which perhaps was the thing she wanted most. Then there were the epileptic attacks, unpredictable, violent and devastating which made her collapse to the ground, shake, foam at the mouth, cross her eyes and squeeze her face. And yet... we’ll never know what world she looked out on when she came out of an attack and smiled, sang little songs, and jumped about – all not for us but for some situations of which we didn’t form a part but which didn’t seem menacing to her. And then she slept as if to recuperate the mass of violent energy she’d released. In the last five years it seemed that the episodes of tension, the calmness and crises were reconciled and the aggression seemed to disappear. Perhaps for this reason the tension towards the change and transformation seemed more harmonious, sweeter, and more interior, perhaps with more serenity despite her visible condition. The change was wholly interior, perhaps deeper and more completed. She allowed her gloves and berets to be lent to others and gave a sweet smile at a request to borrow things. A few years earlier that would have been unthinkable. Then, she never gave up any

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of her things and became aggressive even at the proposal of a lending. I think that the complexity of Eleanor as a person fixes itself in these two complementary moments: the great existential tension in which she seemed to want to intervene in her future, and the aspects of peace and serenity in which she enjoyed her existence and her little world. I think that from the interaction between the tension and peace, the change and growth that worked on her in her life was born. I'll illustrate these two aspects with anecdotes taken from a mass of memories and try to transmit in a concrete form how the transformation in her – often tiring, but continuous – came in small things, in day to day things, which for her in many moments took on a transcendental dimension.

## THE EXISTENTIAL TENSION

Her courage, desire to grow, her love for status symbols, her desire that she be given justice, to find herself in whirling situations, all transmitted the message of her existential tension being in the desire to be: between the most difficult situations at the beginning and her desire to transform herself affirming herself as a growing person. The epileptic attacks tormented her but she went forward all the same. Perhaps it would have been easier for her to accept being treated permanently as a little girl. There would have been some advantages but she affirmed forcefully her wish to grow and the status symbols were a way of expressing that attempt. She wanted to be the object of respect and consideration and wouldn't stand things being done to her which she considered wrong but which were not recognised as such by others. And yet she lived in a circumscribed situation where the motives that seemed inexplicable could come out independently and be uncontrollable.

# •1

## COURAGE

She had extraordinary courage. The epileptic attacks tormented her each day for long periods, five, six, ten, twenty a day. They happened above all in spring. They told us that perhaps the change of light was an influence. She was given drugs but she had many kinds of epileptic fits and for long periods we were unable to control the attacks. She fell to the ground, hit her head, broke a tooth, an arm and hit her face on the ground. Her joy in making things, her curiosity, her love of people, her desire to be in the thick of things never diminished. We didn't feel like limiting her, we let her go everywhere, up the stairs and along the road, but we were always near her in the illusion that we'd be near to catch her. Many times we did, at other times we were unable to do anything and the sense of not being able to help her was devastating. But she continued intrepidly.



(Eleanor at the swimming pool)

She was never afraid of her illness and never allowed it to impose restrictions on her. She had a beautiful little helmet on her head just in case of a fall. Bernard had ordered it on the internet from the USA. It came through the post and was very tough, but soft and a bit stiff, stuffed so as to absorb the force of the fall. It was red with white borders, vaguely in the form of a cocked hat even though a bit rounded. She put it on at school and it looked fine on her head. She wore it with pride and with her black velvet trousers and with her little jumps she was a real character!

Even when she was small she was intrepid. I saw her take her first step. It was a very big room and she went leaning on the wall.

At a certain point she took away her hand and started to go towards the centre of the room. And she went! When she started to suffer from epilepsy she never ever kept herself from doing something amusing for fear of an attack. If they happened, she fell to the ground

and then when she felt better she got up and started again. She had a great faith in the world. During a stroll in Camogli she grabbed a street cat and gave it her crisps while holding it by the neck under her arm. She absolutely loved cows and wasn't afraid of them. She'd gone off with Coca Cola, the dog, into the fields nearby where cows were grazing. She was watching Coca Cola barking at them and at the cows which sometimes charged him, until we arrived and both returned triumphantly home.

## GROWTH

Any indication of growth was a great occasion. The thing that had become too small was very important. There was the comparison with other person to see who was the bigger. The trousers and T-shirt became short, the shoes too tight, the bicycles too small and the seat of the swing was now baby-size. She was very proud of being a big girl, at least as regards age, and liked a lot the comparison with other people which showed she was the bigger.

Charlotte, her great friend, was then three months younger and she spoke of it a lot both in Charlotte's presence and when we wanted to talk about pleasant things. We never spoke about the age of her somewhat taller friends because she took it badly, sometimes becoming sad and sometimes becoming angry. Her torment was that Martin was older by 22 months

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and she'd not managed to reach it. Another personality which often appeared, especially from when she was in the wheelchair, was that of the "little girl." Everyone said she was big, able, patient and courageous and certainly not like those little girls that grizzle and don't behave. When she heard these phrases her little face lit up and she often laughed with her eyes or out loud. Her great friend Michele knew how to speak to her and always called her a "strong young girl" and when she was in the chair you could understand she was very proud of the title.

### STATUS SYMBOLS

Almost everything was a status symbol for Eleanor: shoes, satchels, exercise books, socks and jackets. I don't know how much these things just pleased her in themselves and so removed them from the quality of being status symbols. We started with the uniform for the nursery school, pink and white, or all pink– it was always a pleasure for her to buy a new one. Then there were the swimming costumes: from when she was small she'd go in the swimming pool and the costumes were neither small nor old but for each new course we bought a new one and she was happy. Her satchels were all in almost pristine condition but every year there was the ritual of buying a new one. When she went into shop she'd immediately see the one she wanted and we never discussed the price.

A classic example of this happened in Urbania in a little shop in the arcade where she entered like a little bull to buy a rucksack with a particular design she'd seen in the window. She really liked it and kept it in the following years so we used it when, in the chair, she went to stay with Nunzia and we prepared the things she needed. The new satchel was very important for her. In the five years in the wheelchair she spoke only once, after two years of silence. After some days of great agitation, one afternoon she spoke saying to Nunzia, as if she had just said something the moment before, "I want a satchel." We asked her where she wanted to buy it. She said "At Diego's." She never spoke again.

The diary was a difficult choice too and it got to the point where I bought it for her and took it home as a sort of surprise. Anyway, she was getting too agitated to choose. The bicycles served two functions, status symbols and an indicator of her growth. She really had a passion for bicycles, to look at, push and to ring the bell. In Urbino Albo found for her one with pretty designs and once he even found one with bells and a little clown motif and we put two bells on the handle, one next to the other – beautiful! One day we tried to make her ride a bicycle and we bought her a really nice one,

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a shocking pink colour, and a size which was already a 22. We fitted balancing wheels on each side. She never used it but she looked at it and cleaned it and got angry if anyone moved it. In England her grandparents used to go miles in their Ford Marina in reply to advertisements in the papers to find the right bicycles.



(Eleanor and her Grandfather)

Each summer they'd find two bicycles of the right size and the two smaller ones would disappear. A high moment for her was to know that the 'old' bicycles of last year had been given to younger or smaller children because she'd grown and so needed a bigger bike. This passion continued during the last five years. Twice, for a birthday and at Christmas, we gave her a helmet which we went to buy in the Mondo Bici store. She studied them all with great interest: the first time we left with a red and black one of aerodynamic design and the other was blue and black. For a while she held them in her arms on her knees and looked at them with joyful smiles. We hung them on the pole supporting the bag was that contained her food. For a while she was overjoyed, then became used to the helmets and finally the interest waned. Her desire to express and realise herself through choices conflicted with the great difficulty she had choosing. She always chose her own clothes and shoes but it was very difficult for both of us when she entered a shop. She said no to everything that was shown her but that

was only because she didn't know how to choose, or perhaps she wanted everything. Then she'd get very, very angry, and would often hit and scratch me in the shop. It was very difficult. With her father things went better. They went into a shop and came out quietly with something. Perhaps Bernard got less flustered than I did. But then there was a sports clothing shop with a very kind owner Paolo who with much patience brought her the things that suited her, she tried them on, and we all walked out calmly. She'd gone to Paolo when she was in her chair together with Francesco to buy a pair of shoes. They returned with two, red ones with white stars and little, laced, high-heeled shoes made of cotton, a very nice pair, and a pair of black trainers. Francesco told me that the white star shoes were also available in green and blue but she very decisively only wanted the red. In her choice of clothes she was very decisive and I found that area easier.



(Eleanor and the Kangoo)

She liked strong colours very much: T-shirts in violet, green and yellows, and she made a dash for them pointing if they were hung up in the shop. We rarely went into toy shops and when we did the experience was so traumatic that we finally had to stop. At the market it could go either way. We always met people we knew and she liked that.

This continued when she was in the chair. Many people stopped to caress her and she liked that. We always bought something – as a minimum some bits for the scu-bi-do – and that was often enough to keep her happy.

Once she cried because that wasn't enough. At the market we bought together a beautiful pair of gilded shoes. They were available in silver, and green, but she made it clear to me she wanted only the gilded ones. It's impossible to describe the way she expressed herself in such a clear manner without using gestures or speaking about it. I think she was very proud of her silver Kangoo, "Eleanor's car."

When she got into the wheelchair she went everywhere, to the Conad supermarket and the market and to meet friends at the Urbino parties.

#### JUSTICE

She had a great sense of justice with regard to herself and she calmed down only when, as she saw it in her view, justice had been done in her regard for a wrong. Many of the stories she liked to hear recited to her revolved around the theme of wrongs she'd suffered and justice done. One winter when she was 4 years old both she and her brother had one cold after another and we were all kept in the house for many days. One day Bernard and I rebelled and we took the children in the car, all wrapped up, to Fossombrone for a trip, even though it was very cold. When we got to the place Eleanor got out of the car and took off her jacket. I really exploded at this, took her by the shoulders and shook her, screaming at her. For years she wanted to hear the story of that afternoon and each time she stuck up her finger and said "You shouldn't have." Eventually I asked her pardon, saying I shouldn't have shaken her like that. She never alluded to the story again. She liked immensely another story with a mixture of justice done and a narration about herself. This is it: "One day Eleanor told me that Enrico had given her a punch in the stomach. So, when he came to play with Davide I called him and said, "Enrico,

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# 5

come here. I want to talk to you.” He came and I said, “Enrico, Eleanor told me that you punched her in the stomach.” He replied “No. I’ve just arrived.” I said “It wasn’t today; it was the other day at Loredana’s birthday party.” He said, “No.” I said “Enrico, Eleanor is small and fragile and you’ve no need to push her.” And he never pushed her again.” The high point of the story was the two words “small and fragile” where Eleanor’s little face lit up with pride. This story was always among those preferred by her. Enrico is now a doctor and a father. In Genoa uncle Luigi, as a joke, sprayed her with water from a watering can. It was a story without a resolution. Each time Luigi was mentioned she stuck up her finger, saying, “He shouldn’t have!”

THE VORTEX

She loved little babies immensely. She looked at them in their cots, talked to them with a very affectionate voice and touched them if the mother allowed it. Once she held one in her arms, well supported by a sofa and with someone near, and she really loved doing it. The young children had differing reactions: once in a park in England she jumped on one dressed all in pink with bobbles and a little pair of shoes. The child was practically speaking motionless just sitting on a swing. She pinched her without any warning and the parents called a policeman. I tried to escape unobserved but he followed us. Bernard stopped and told him about Eleanor’s difficulties and it all finished there. She also scratched without warning the little girl of some friends who didn’t pardon her and didn’t want to meet her any longer. They had been very dear friends.

These were the incidents that happened when the situation got out of hand. Usually things went well but you needed a lot of energy. I smiled a lot and in each place we entered I looked around immediately for an ally, either a pleasant-looking mum with her children or just someone with a nice face so that in the recreation ground or in a café, in a train or even a plane we could have somebody as a point of reference. She found it easier to be with a single person than with lots of people. It was the latter that she couldn’t cope with; she got lost and became very agitated. That was what happened more or less in the shoe shops: if there were too many choices she couldn’t cope. Once the stress was too much and she couldn’t cope and there were scenes. Sometimes she’d scream, or hit me, and in public it all was very difficult. When scenes happened at home there were more resources: we’d send her out into the garden or sometimes I’d shout. If Bernard was there he knew how to intervene: she’d be put on the sofa under a warm blanket and she’d stay quiet. This procedure had been advised at Mestre and for a while

it worked. During the scenes she suffered a lot and went into a spiral from which she didn't know how to exit, becoming increasingly aggressive and angry. This usually happened when she was too tired after a day of excitement or activity or tension because of other things or she went beyond her limits of endurance. Perhaps we didn't understand when we ought to have intervened and stopped her, and then the situation got out of control. She had a relationship with food which occasionally produced some problems. She absolutely loved chocolate and Coca Cola but they made her very ill. Just the tiniest quantity was enough to make her very agitated and go out of her mind. If there was a bottle of Coca Cola in the next trolley at the supermarket, she became a little animal and attacked you with shouts and, if she could manage it, kicks. Once she went into town with Nicole who wanted to please her and bought her a cone of chocolate ice cream. There was total pandemonium, with shouting and scratching. The last gesture she was able to make before she lost control of all movement was to point with a finger at the Easter egg hung up in the corner of the room.

There were people whose company she liked even when she felt bad. Gabriel was her great friend when she was 6 years old. He was perhaps a year younger but they had a passion for bicycles in common and also motorbikes. Both wanted a motorbike when they grew up. With him she was always at her ease and calm. He expected her not to get agitated and she didn't. It was the same with Federica, the friend who had the hairdresser's Eleanor went to. Federica spoke in a very direct way, asking her if she wanted her hair short or very short, if she wanted to look in the mirror, and telling her to stay still because she'd got scissors in her hand, and Eleanor stayed still and attentive. With Rita too she was quiet. Rita was her teacher for 5 years, those wonderful years that she passed in the middle school (she had to repeat a year twice). Rita was always calm and spoke to her nicely and gave her security. Rita gave out the message that she wasn't going to run around after her. They spent many hours a day together, did a lot of creative teaching activities and only rarely was there an accident. Many of the teachers who in the course of the years occupied themselves with Eleanor came with us to Mestre, and some of them found it helpful. Eleanor really was a situation outside the normal parameters and it wasn't their fault if they found it difficult to frame the problem and to set up objectives for teaching that could develop both the intellectual and the behavioural side. The suggestion at Mestre to the teachers was always the same: help her to interact with her companions

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taking into account her difficulty in expressing her feelings, and propose programmes to her as much as possible similar to the normal ones, restructuring the content using simpler language in almost all the subjects. One teacher made her study Manzoni's *The Betrothed* with her classmates and another *Romeo and Juliet*, while another worked with her on traditions and customs. In science she studied the movements of the earth and sky.

She gave me lots of strength, physically too. When she was small sometimes she was a real handful, and after difficult moments I felt so emptied and tired. She understood, jumped and came into my arms and I felt a real flow of energy which went right through me and then down to the ground, a recharge. Many times I sat near her, held her head, said she was dear to me and she smiled at me with a very deep joy – she communicated it to me. I looked at her, and we were very happy. Looking after Eleanor I used an extraordinary amount of energy: all that had to do with her had to be done very well and you always needed to look ahead and give yourself objectives to reach. Even in those last months of her life, in which she was so well, I thought she needed to go a bit further than the limits, that there was space to move further on. Dr. Vitali, too, had reacted in the same way to her good health and said it was extraordinary that she was so well after almost 5 years of such a difficult bodily condition and he tried to extend her ways of communicating, suggesting two little flags, one 'yes', the other 'no', which she could point to with her eyes. This went so well that I tried to re-teach her how to speak. I

said "Say hello to daddy" and then I held her hand very tightly to give her strength. She tried so hard, watching how to move the eyes and how she could swallow. We stayed together in high tension for a couple of minutes. Then, when she asked I told her she'd been very good, I kissed her, we laughed and she was pleased. It was so tiring but the strength I gave her helped me in all areas. I worked a lot, created projects at work and planned the garden and socialised.



(Eleanor with Andrea on tricycle)

# 4—

I got tired a lot, never having enough time for everything because she absorbed so much, but I had the idea that everything ought to be done in the fullest and most intense way. SERENITY

I'll write here about Eleanor's quieter moments using the themes of affection, friendship, the daily happenings, about her being a joker, the celebrations and the happenings we remember with pleasure. These were the sweet moments in which it was easy to be with Eleanor who was happy while she was left to grow and live in harmony. She was very sensitive, affectionate and compassionate. When I had a surgical operation I let her see the gauze fixed with plasters and I explained that it had to be changed and each morning she gave me a caress before I changed the gauze. She was very concerned about the people dear to her. Once in Urbino it had snowed and we spoke about the difficulties of getting out of the car, putting on the snow chains and being snowed in. She, very worried, said "And Nunzia?" because she knew that Nunzia who was very dear to her lived at the bottom of a winding road as we did. This sensitivity and sense of cooperation extended to things and animals. When she was little we took our summers in York in England and in the road where we lived there were always lots of cars parked. If she saw a stain on the bodywork or a rusty part she would stop and give the car a kiss. FRIENDS

# •1

She had many close friends: as a small girl there was Davide of Sasso. Davide was a handsome boy, tall and thin, 4 years her senior. He did his homework diligently and when we asked Oriella about him she often said "Davide is studying." For years we've recalled that phrase 'Davide is studying' and she liked it a lot and laughed. In honour of Davide we've had many generations of cats and dogs which were called Davide, and not everyone realised why. In the kindergarten there were 4 Eleanors: Eleanor Worthington, Eleanora Maroccini, Eleanora Battistelli and Eleanora Pagnoni. The last was always together with our Eleanor and they embraced each other so much that I thought they seemed one person. These Eleanors formed part of our story for many years and Eleanora Battistelli took the lead. In 2003 when Eleanor was very ill. I asked for the support of everyone who loved her to help her to stay with us. I called Maia in the morning and she came in the afternoon with Flavia and Sandra. I called Rita who came immediately and started chatting to her. I called Viv and Michele. Rodana came with a beautiful new dress for her. All her classmates came and everyone helped to keep her here. She and I passed whole nights singing and telling

stories because she couldn't breathe and we sang songs to the rhythm of her breathing. She loved Aaron, her schoolmate, a lot and I think they talked about boy and girl, which she liked, because each time I spoke about them her eyes flashed. When she was very ill I said her school companions were coming and she was waiting for Aaron. They were late and she lost her strength and nodded off so when Aaron and the others came it was too late and she was asleep. From when she was small she interacted with other children with a particular vivacity, with a particular fondness and smiles. It was a special day for her when Edoardo, Valerio, Alfredo and Pierpaolo came. They gave her a kiss and had a conversation with her. She captured the imagination of other children too. Listen to this description: Anna, Marta and Irene sent her a poem entitled "At Christmas" – At Christmas we have to be very good / If we want to get presents / We have to show to the entire world that we really love others / And that the joy of all the people rises to the top like a life-belt.

In the last two months of her life, Eleanor discussed with Monia her marriage with great enthusiasm: the celebrations, the church, the clothes, the flowers, the music, the photographs, the making of the home video and the car.

She'd seen Monia's wedding dress and she had been the only one to see it apart from her mum and her aunt. They'd made plans about Eleanor's dress: there was one in a pale green embroidered with silver that came from India, a present from Nunzia. And then there were the flowers in the hair, and the silver sandals. My proposal of little shiny yellow shoes, very nice ones, which had been sent as a gift by a friend of mine, were refused by Eleanor using her face and eyes in a most expressive way. During the week of the wedding of Monia and Luca three people dreamed of Eleanor: Viv, Sabina and Flavia. In the church I felt an impish little spirit next to me who made contented little jumps.

#### ACTIVITIES

She was very intelligent, even if her body didn't work. She had a great sense of direction, like her father and grandfather. When she was small she used to sit in the front seat of the car and say 'straight ahead', 'right', 'left' and made wide gestures with her hands. She liked languages a lot and had an ear for them. For year she'd repeat 'le filet pour la petite' because a sleeping car attendant had said it to her on a train to England. She wanted to learn German which she had heard Gabriel and Iose speak. She was bilingual, in Italian and English and changed language according to the speaker and the subject matter. With her brother she spoke in English if they discussed the sweets

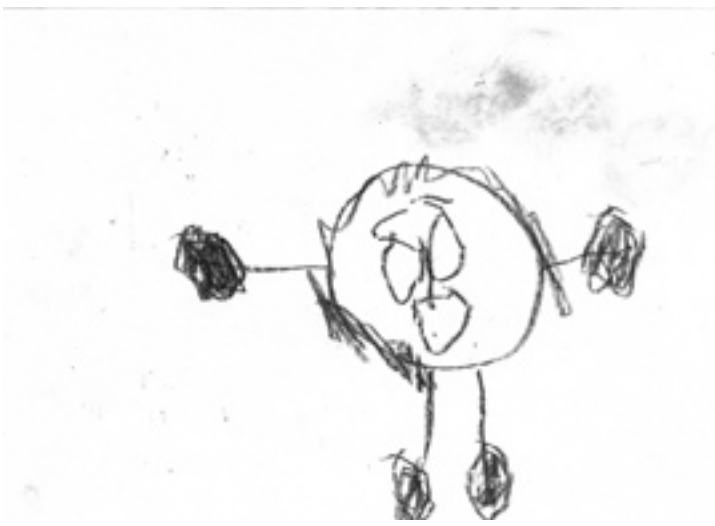
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typical of England, Jelly Babies, Smarties, and Mars Bars: It was their private world of fantasy and dream. With the grandparents on the phone she spoke English and with the grandmother she came in as a chorus when she sang Yankee Doodle on the phone...

With Bernard she had a complete understanding. They always spoke in English and every now and again she'd ask him "Daddy, shall we keep mummy?" and he, with equal seriousness, replied "Of course, Eleanor." I never understood if these two really tried to weigh up whether it was worth keeping me or finding something better, or if she wanted to be reassured through the fear of losing me! She could draw very well and used a lot of concentration and care. She liked to draw completely on her own and yet seated near someone who was also drawing on their own and without any interaction. She often copied the page and the printed capital letters, especially the A, and R, but back to front, the E, but with four instead of three parallel lines, and the O. The letters covered all the available space and there was no start and end. They overran each other's space. Who knows if they wanted to express being overwhelmed by the excess that they contained or, perhaps, the ability to look into the infinite that repeats itself. Sometimes she'd make a border either completely around everything or in two parts. At other times she'd draw her little men. These were carefully positioned in the centre of the sheet, or had a lot of space left around them. They had a head, eyes, mouth, arms which came out of the head, legs and feet. The eyes were always very big, round and without pupils, a little like the little alien Etabeta.

(Eleanor's little man)



The mouth, hands and feet were big. Sometimes there was hair, two shocks of hair from the centre of the head to the ears. The little men were always drawn so as to be identical, and this from her earliest years.

If she was angry the men had a real scowl. At the Institute of Art in a course of computer drawing she animated one of her little men and it was presented together with the work of her classmates and shown in the Sala del Maniscalco. Her little man

danced and was very impressive. At the edges of the drawing of the little men there was a house which wasn't separate from them. The house had windows and a door, or eyes and a mouth, and had a roof or a tuft of hair. When she was really happy or quiet she did other drawings. With great care she'd draw a border to the sheet and then divide the space inside the border into coloured spaces, usually two or three almost vertical strips, thickly coloured and without holes.

It was real abstract drawing.

She liked things being in order a lot. When she was little, really little, maybe 3 years old, she and Martin played in the red room, a very big one with the walls a brilliant red and full of their games and a pile of toys. Every now and then I'd say, or shout, "Come on you two, tidy the room up." Eleanor, on her own, made a great space on the carpet in the middle of the room, put all the toys against the walls and she was very proud of the result. And when she was in her chair she was greatly pleased when Monia or Paola or Oriella put her wardrobe in order: all the T-shirts and pants nicely folded, the T-shirts on the second shelf of the cupboard (in the first there were the medicines etc), the sheets and the duvets in the third drawer, the trousers, sweat shirts and the outfits and the waistcoats in the wardrobe, all placed one above the other in many nicely divided rows. While they were putting things in order it was always possible to eliminate some clothing that was too small or discoloured or ripped and it was clear that Eleanor was very pleased to see them finish in the dustbin. At home we got a lot of help from her in all the things we did and she liked it a lot. Her real heroine was Oriella and the little song 'Now that you always clean' was often repeated. Perhaps one of her better periods was that of the middle school, between 12 and 15 years old. In the hours she did a great deal and with a will. We've got photographs of when she used the Hoover, when she made a pizza, when she took the ashes out of the fireplace and when she put the woodpile in order. We did all the things with her. She particularly liked kneading the dough of the pizza. When the dough was ready she'd raise it above her head and then throw it on the table to flatten it, with a lot of emphasis and pride in her work. She liked to add the toppings. All was cut up beforehand and she put it on the pizzas and they were excellent. She took the ashes from the fireplace with a pride in her work using the shovel and bucket, leaving practically nothing on the floor. She really liked to wash the car, and on her own: the bucket with the water and shampoo, the cloth, the water pump. The important thing was for us to close the windows and then she did everything

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in a whirl of water and puddles and got infinite satisfaction. She hated having her hair washed and usually cried and screamed – until one day, with a lot of determination she went into the bathroom on her own, opened the cold water tap and put her head under the tap. From then on she often washed her hair herself seated inside the bath and holding the handle of the shower spray. The water went everywhere and in the end she accepted some help without getting angry. From when she was little she liked to prepare the vegetables for the minestrone: she chopped up the courgettes and potatoes putting a large cloth underneath to stop them slipping and then put them into the pot. She knew how to make tomatoes au gratin which she liked so much. I cut up the tomatoes and she put on the olive oil, salt and breadcrumbs and then put them on a pie dish in the oven. She ate them with a hearty appetite. She also knew how to make roast potatoes. She cut them up, added olive oil, salt and rosemary and popped them in a pan in the oven. From a very early age she'd learnt how to use scissors and knives as normal instruments. A lot of vigilance was always needed: the important thing was to be able to intervene if necessary.



(Eleanor cooking)

Usually it went OK. I only remember some three occasions when she threw a pair of scissors or a knife, but we were always alert and there was never an accident. These operations were a source of extreme pride for her: from when she was small and then when she was in her chair. There was this story I told her and she loved it, smiling and with flashing eyes. "How Eleanor had always been a sensible child and even as a little girl she could use knives, scissors, saws, scythes, files, pincers, pliers and hammers," and the longer the list the more you saw her pride in recognising herself in that great amount of good sense. She knew how to make broth, which she liked a lot: saucepans, water, stock cube, small pasta shapes and then I'd put it on the stove. She could make popcorn too: oil in the pan, corn, covering the pan and putting it on the stove. When she heard the pops she was amused and the game was not to take the cover off. But sometimes there was popcorn everywhere. We took the popcorn with us on our strolls



(The game "Make a game")

and on picnics. In these strolls there was only one way to make the children carry on walking when they started to tire and that was something to eat, popcorn or crisps, and usually it worked. Once we tried sewing using two concentric little circles of wood and the material in the middle with the needle going from underneath to the top and vice versa. She didn't like it and we did little of it, apart from a pinafore for a doll.

She put the wood for the fire in order very attentively. We did it together. Bernard started the first layer and then we all collected the wood from where the supplier's tractor had dumped it and we set up the different layers. Eleanor's were very well aligned.

She had a passion for animals and sometimes we went to Schieti where there was a herd of hefty white and black cows and their calves kept in a separate enclosure. We passed hours looking at the cows which lay down slowly or got up, grazed and then did little wanderings before lying down again. You could understand that she always hoped there'd be some

dramatic happening, that one got free or that they fought each other. But she still liked them a lot, just peaceful as they were. We played at "mamas": we stood at a distance facing each other. Then I opened my arms, saying, "I'm the mamma" and then she'd race towards me and I caught her in my arms. Then we did the contrary with her taking my place. She liked the game "Make a game" when she was older. We had a sheet of paper and two different coloured pens, one for her, one for me. She drew a line and I made another attached to hers, then she mine and so on, counting points without any real rules until at the end one of us was declared the winner. She won almost all the times but occasionally I'd win because I thought it was an educative gesture. But she grew angry and cried. Then Bernard and Martin said to me that she'd got enough frustration in her life as it was and it didn't help matters giving her more. From then on we amused ourselves even more, talking about whether it was her turn or mine, how many points she had, and we laughed a lot.

### THE JOKER

She was a real jester and greatly amused herself. When something caught her imagination her eyes flashed and she'd

have a little urchin smile. When little she was fascinated by talking boy and girl, and she would rejoice at that kind of topic. She invented a person we didn't know at all: Rabaltus was an alter ego, a name she'd take when she amused herself fooling around. She'd put one hand on her head, the other behind her back, did a little ballet dance – and there he was, Rabaltus! There was a lot of laughter. Whenever she played a practical joke she'd say Rabaltus. We don't know what she was thinking when, in the final five years, she'd sometimes wake up early in the morning roaring with laughter. They said it was a reflex reaction but for us it couldn't have been because when we went to see what was happening we found her really laughing with a lively face and happy eyes. Sometimes I'd say, "Eleanor, are you thinking of Francesco?" but interpreting the motives of her laughter was difficult. It was always easier to understand why she cried. We played at clowns and we had a special number: I announced to the friends that Eleanor was going to serve the coffee. She entered with the tray and then in front of the friends she let the tray fall to the ground suddenly while she laughed and laughed. She liked to lay the part of the 'little informer' a lot, and this was the game: for the birthday of Martin or Bernard I told her in secret the present I'd prepared and she assured me she wouldn't tell them. Then she went to Martin or Bernard and started to talk about the present. I said "Don't be a little informer" and she laughed with a very crafty – looking face.

#### CELEBRATIONS

•4

She liked these a lot, and the visits, the occasions for staying together with others and the guests. If someone agreeable came to the house she immediately asked if they could eat there and then if they could sleep there. We went to many wonderful parties: one at the K2 of Trasanni organised by ANFFAS or VASIS. There were lots of people, a live orchestra and little tables. We stopped till 2 in the morning, dancing the whole evening and then we sat at the tables or walked around saying hello to those we knew. She danced with a lot of rhythm, sometimes using her arms or singing and shrieking. She really let herself go with tremendous merriment. She liked the Carnival a lot and making the costumes occupied us for weeks. You started by deciding how you wanted to dress up for the school celebration and the parades in Urbino. Then we went to Cocci to buy the stuff. The assistants were very patient as we chose the fabrics and colours and Martin and Eleanor were very well behaved. Then I cut and sewed and something came out. She had dressed as a bottle of Coca Cola, a tin of Sprite, a butterfly and a flower.

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The first was the best, all red, with Coca Cola written by Bernard on a silver fabric cut and glued to the costume.

We went along the roads of Urbino and she was calm and content. Other occasions for celebrations were the processions at the end of May. The procession started from the Mainardi chapel with the band, the Madonna carried shoulder high, then the priest, the band, the men and then the women.

The Ave Maria of the rosary was well cadenced with perfectly equal intonation which she liked a lot. When she was very ill and we wanted to keep her here with songs and stories we said Ave Maria with the same intonation and she liked it a lot, as if the rhythmical, repeated phrases carried her to far worlds. After the rosary the band played a song and we all sang "We want God, Ave, Ave, Ave Maria" All this pleased her immensely and we sang it a lot during the nights of the spring of 2003.

When the procession was finished there was the visit to the chapel of the Cella di Pietra and the return to the other chapel and we sat outside waiting for the mass to finish.

There was Egidio, the master of the band, a great friend of Eleanor at the Francesca centre, Lucio, another great friend, and then all the affectionate greetings given by the neighbours. And finally there was tea-time which was really worth waiting for: ham or pork rolls, chocolate tarts, big, two-coloured iced doughnuts, little cakes, all excellent homemade food. To drink there was Coca Cola, orangeade, Sprite, fizzy drinks, and for once Eleanor was allowed a free choice. She went up with her beaker and they gave her all she asked for. She drank one beakerful after another. For once I said nothing, although I knew she'd feel ill afterwards, but it was such a special day that we gave her free rein.

#### OUTSIDE THE LIMITS

She had a strong sense of amazement, of the wonderful and of extreme situations. Like her father she wasn't interested in mediocre things. She had strong reactions in front of strong experiences: when she was small we went on a school trip to the Frasassi Caves. When we entered the cave and the view was suddenly in front of her in all its grandeur she remained completely still for a moment and said nothing. The same happened when she opened a packet in front of a very big stylized and powerful black and white calligraphy. She was greatly amazed at the festival of San Martino of Verena where there were walks in the woods decorated with coloured lanterns, songs and a meeting with a horse. She loved Halloween. Once we carved a pomegranate and she had a flash in her eyes as she did it, a sort of 'little Halloween' character. She had a dreamy face when we read the story of Max

•5

in his wolf costume who met wild creatures: “And they were frightened and called him the wildest thing of all and made him king of all wild things. And now, cried Max, let the wild rumpus start...”

She always had a flashing smile of enthusiasm for dramatic stories, situations outside the normal limits which introduced boundless possibilities of transgression of some sort and broke through the boundaries. She found these possibilities in normal life which she didn't allow herself to be overwhelmed by but recognised there a meaning that transcended it. Or perhaps she liked to identify herself with stories of transgression as she liked transgression so much. The stories were repetitive: our dog Davide savaged our hens and in the morning there were bits everywhere. Delia and Antonio shouted that our black dog was catching their hens and there was talk of a stick and shouts over the fields. “Crash!” she said with a glorious sound when she heard of some collision or of the possibility of some such thing happening. The real crash we had in England when a car hit us and wrecked the car, and from then on ‘crash’ was said with great conviction and with flashing eyes. She liked sports and transformed them into extreme sports. She had a very daring imagination and found a way of joining her possibilities to what the game required, and that was sufficient for her. On the inflated bouncing castle and stands she rarely jumped but dived instead, and then stayed seated looking greatly amused at the other children who jumped.

Another of her passions was the skateboard. She had one in shocking pink and green, which she liked a lot. She crouched down and we pushed her or she would hold our hands to keep

her equilibrium and then she pushed forward balancing using her feet. This she'd do over and over again with real pleasure. In Urbino they didn't sell skateboards and when finally I phoned a shop in Pesaro, Bernard went to collect it, but it was too late for her. However, we kept one under her bed and before getting her into her wheelchair, sometimes Nunzia would let her dangle her feet above the skateboard and you could tell from her smiles how she liked it.

(Back lane)



# .6

On the swings we had to push her really high and she shouted with enthusiasm, her eyes closed. From when she was little we'd put her on a revolving chair and push her along until she seemed almost white.

## THE STORIES

Here are some of her favourite stories about herself, her affections and unplanned, dramatic happenings. One was to do with Thorpe Street in York where we lived during the summer when she was little. The back street was the domain of the children. The back gardens of the terraced houses overlooked each other. There were no cars but lots of bicycles, balls, dolls and mothers who went in and out of their houses keeping an eye on their children and doing the housework. All of them spoke with a strong local accent which was easy to imitate, even for me. There were lots of children who played with Martin and Eleanor, some more affectionate than others. Obviously it depended on the mothers: Julie had 4 children of ages around our two and one of them, Joanne, was a merry little urchin near Eleanor's age. She and Eleanor dressed identically, one pink and one blue, and were "the two little angels" who crashed down the stairs and brawled. Christine was a treasure, and her children Katie, Mark and baby Adam, and the dog Jess were among Eleanor's closest friends. The story implied repeating the sounds of Thorpe Street: the mother who called the children when it was time for dinner. I'd repeat the names of the children using the right accent, Keeiti, Maaark, baby Adaam, Jeeess, and Eleanor burst out laughing. She also liked stories that were a bit more dramatic: in the back lane Graham would play, a thin little boy, a bit of a wolfish cub with a dog that had sharp teeth. One day Graham incited the dog to seize Martin and Eleanor's ball and he burst it.

This happened twice. It was one of her favourite stories and when it was finished Eleanor raised a finger and said, "He shouldn't have!" A different Graham formed part of our stories too. One of our friends said to Eleanor that she was "the strongest girl I have ever met." Eleanor was very pleased, showed her arm and her muscles and laughed. Then there were the stories of Earby park: she's with a bicycle – it's not clear whether she's seated on it or pushing it – and there are swings for the toddlers with their little 'boxes' for seats and others with the plank for those children near Eleanor's age; there was a swimming pool where mostly the dogs had a swim to get the stick thrown in by the kids. They jumped in to take them and came out completely soaked and dripping. Then dinner time came and the grandmothers came to call them.

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These stories were told often and listened to with the same concentration, as if the repetition became a kind of singsong that took her to far worlds where she could concentrate herself outside her limitations and find the strength and inspiration to be, to grow and to transform herself. When she came out of the reanimation unit, we never left her for a moment on her own. We told her, very softly, the stories of when she and her brother were little. Martin was very good: “Daddy, do you remember when we were going to the park ...?” and she was very attentive with a face that changed expression according to the stories.

Well, I'd like to conclude:

Almost utterly  
Ceases my vision, and distilleth yet  
Within my heart the sweetness born of it

(Dante, Paradise, XXXIII, 61–64)

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# PROJECT FOR LIFE

## FROM NUNZIA

“What a sensible little girl! How able our Eleanor is! What an example she is to us all! Clever little thing! My little baby! Now... a little baby? No! There are no longer little babies here!” These are the words that Giuliana as mother used when sitting on the bed next to Eleanor when she enfolded her in her long arms as if to create a little cleft, a little nest in which she felt welcomed, warm, calm with her own feelings. She was happy to reassure her mamma and by intuition felt the great peace of heart that that moment held.

We often met at the birthday parties in the houses of our friends with whom we shared the joy of bringing up children. Eleanor was a lively young girl, full of energy and enthusiasm, noted by others. She ate good healthy portions of food with relish. Our important friendship began on a particular day, the 8th of March at the end of a winter that was retreating defeated by warm scents that recalled spring and summer days.

I'd decided to take a short break from my work and go for a walk in the town to celebrate the return of the spring days with a brioche and hot drink in the café in the Piazzetta delle Erbe. Once upon a time the café formed part of a grocer's in art deco style. “Pizzicheria” said a sign above the door and the 70s foreign food products were to be found inside, above the wooden platform that led to the counter behind which two kind sisters took turns and each time revealed different feelings, talking of an exciting surprise at having reached a familiar place or better a place that brought old projects to mind or resuscitated them. While I waited sitting in front of the shop door, taken up by my own thoughts, I saw Giuliana enter with Eleanor with her particular way of walking energetically, youthfully, at times somewhat boisterously. We recognised each other, said hello, and I was invited to sit at their table. A friend often spoke to me of Giuliana saying that we both “resembled” each other, something that made people think we were sisters.

Eleanor was dazzling, her vivacious clear blue eyes moved quickly as she glanced at the plates with cakes and at the people there. She seemed interested in me. I was giving my total attention to the discussion which little by little grew up between us. There was a second important meeting at the beginning of the summer, this time at the entrance of a well-stocked bookshop below the piazza. I was looking for a book that might help ease some problems I had at the time. Giuliana asked if she could put up a notice in the shop.

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She was a little agitated and didn't know quite what to do. She had university work to do in the following weeks but her dear friend who often accompanied Eleanor in the afternoons had a swollen foot, had difficulties walking and so couldn't be with Eleanor. There was little time to get a substitute and Giuliana hoped a student might help out and asked me if I knew anyone. I said that at that time I had some free time. As a family we were getting ready for the summer holidays and gathering the fruit to make jam. I looked after the vegetable patch and the vineyard with my small children and organised the sale of the products at a market or country fair. "I'm free at the moment and if I can help I'm more than willing. I've been living with my four children for a number of years in India and Nepal. If you like I could help you out and in the meantime you could get yourself organised." We agreed that I'd begin the following week. I had met Giuliana's friend at her house and after a few days Eleanor came with her mother. My husband and the two younger children were at home with me. We sat at the kitchen table talking about many things, sharing our interests in a varied life that called for great seriousness and an ability to interact with others. My husband decided to show Eleanor a game with the fingers of the hands which normally was of interest to children, but Eleanor interpreted it as a hostile gesture, used a lot by those of her own age, and reacted aggressively. She felt offended and started to swear and get agitated, so much so that the visit concluded with Eleanor in the car waiting for her mamma, without any change at all in her behaviour. A few days later I called at her home, a big comfortable house with an upper floor and many areas of different sizes. There were lots of books, a piano, a fireplace, a window in the English style which took up all the area of the living room which opened with a curtain onto a large garden with many different trees and bushes. Giuliana's friend was waiting for me in order to show me the set-up of the house and I sat in an armchair in the living room waiting for Eleanor to wake up after her usual afternoon nap. A heavy curtain with red flowers hid the main entrance and the corridor which gave access to the different rooms and stairs, while a large opening to the right revealed the kitchen and so gave a sense of continuity to the two areas. We started to hear noises coming from Eleanor's room. I thought of getting up to greet her but then thought I'd just

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wait for her quietly seated. The sound of irregular little jumps on the stairs meant she was coming. I warmly greeted her and was presented to her again. In her lovely clear eyes you could read the surprise she felt at seeing me again and a certain interest in knowing me. So our long friendship began. We met for a couple of afternoons each week. She was finishing her third year at the istituto Statale d'Arte, was accompanied by Bernard, Giuliana's husband, to school, returned home and lunched with him, then went to lie down for a nap. I stayed with her in the living room with a cup of tea, lots of books and sometimes I'd play a tune. During the school holidays we took short walks along the pavements around the house, accompanied by the little dog and cats who played about us. Paco, a dog, let himself be stroked peacefully and the cats stuck their tails straight up and went in front of us. We talked about many things and she liked to ask me various questions which she repeated a number of times, like "Do you know my mummy? Isn't she called Giuliana? Isn't she tall, as this?" she asked, showing with her hand a height not a little taller than mine. "Has she got short hair, a little grey?" I asked. "No, black," she replied with certainty and stopped and gave me a serious look as if to affirm her own opinion. "Yes, I know her. She's my friend," I replied.

(Eleanor dances with her ducks)



At that she responded with joy shown in big smiles and repeated jumps reflecting the lightness of heart that the image conjured up. Sometimes her brother Martin, who lived in England, passed some of his vacations with the family and came with us on our usual walks. After the first part of the level road we went up the hillside at a brisk pace to the point at which our gaze took in the mountains of Carpegna and there we stopped to admire the landscape: the green little hills and woods which fell rapidly towards the valley which moved away from us in undulations; the bold expanses of cultivated fields cutting into the hills here and there where the tractor could reach, and the abandoned houses that were rebuilt further down and others rebuilt higher up where the road to Urbania came with its continuous curves. Martin thought that the charm and beauty of the landscape was disturbed by the sight of the coloured cranes which soon started to stick up one after another. I thought about the total silence that wrapped these spaces



(Eleanor cooking)

at certain points all thicket and unreachable where only a tiny rivulet managed to make its way, or at others were changed by man with the passage of time. Eleanor remained quiet. Who knows how she reacted to that world that was so simple and normal. Then she felt tired and we all returned home singing. On the way I collected some varieties of aromatic herbs, wild mint, fennel and lemon balm.

I put them in front of her nose to smell or used twigs of broom to form little nests in which to carry home a dry acorn with its 'hood' still attached, dry berries of dog rose, small wild roses or poppies with their very delicate petals. Eleanor didn't show any great interest either in the walks or the natural world but she got excited when we arrived home and she saw her fuchsia-coloured bicycle or the scooter mended by Bernard. Even the animals that lived happily outside the house were sources of interest: the ducks and geese with their particular walk, the hens and chicks with the cockerel that led them. One day we went to buy a couple of pigeons which

decided to make their nest on the window sill of Eleanor's room. One of the creative activities she was keen on when we returned home was the collage. I put the glue on the little pieces of coloured paper, gave them to her and she, using great energy, knew how to compose the mosaic patterns, thus showing a great artistic sense and an enthusiastic, lively energy when she was sure that all was firmly glued in place and she beat it with her fist. She was very proud of her strength and showed me her closed arm saying "I'm strong." I replied that we seemed to be in a post office when they still used the stamping pad! Sometimes I'd pass her the scissors as she liked cutting things up, magazines or old flower-order catalogues. After she'd looked at the pages carefully she attacked them with the scissors letting the pieces that didn't interest her fall and keeping others, looking at them again and reorganising them at certain points with a greater precision – but it was difficult to find a logic in her choices. She was allowed to use the scissors and knives because she liked to help in the preparation of the meals and was aware of the attention needed. She looked at the utensils, looked at me with a pleased look and then cut up the courgettes and carrots with a particular diligence. She didn't like cutting

the onions and was not given the job. She could light the kitchen stove only when she cooked the pasta broth and followed all the stages right to the end. She tended to alternate periods in which she had a hearty appetite with those in which she wanted only to eat certain things and certainly she was jealous in this sense, as were her peers too. She liked to help me when I prepared the flour mix to make pizza, biscuits and tarts but I remember the particular almost fearful expression she had when we made gnocchi, and she wasn't keen either on boiled potatoes when I asked her to make some pasties. After an expression of amazement passed over her features she pulled back her hand and despite my repeated requests to collaborate she just looked at me and didn't help. Perhaps her embarrassment came from the impression of something living that the warmth of the pastry conjured up and it was easy for me to associate it with the delicacy with which she caressed the faces of the new-born babies that attracted her a lot. Eleanor had an understanding of life's fragility. She ate heartily but she had difficulty swallowing a mouthful, a part of which was held at the mouth outside the lips with her saliva, so that her clothes and even her shoes were always a bit stained by food or dribble which we cleaned away with a sponge when possible. But it wasn't unusual to see a certain discomfort among those who came to dinner for the first time. Some expressed disgust; others didn't look at her. Once food is inside the mouth it becomes part of us, an intimacy which it's difficult to observe. Her system rejected certain substances like milk or caffeine and we tried to limit the use of those foods that contained them but it was difficult to refuse her soft drinks or ice cream. Autumn came and I had to make preparations for a new visit to India with my two younger children. My husband had already left and the two older children stayed in Italy in Pesaro. A Venetian student was to remain with Eleanor, and Giuliana was going to take us to the station. We left our home and our animals in the hands of a local friend. So one morning we loaded the suitcases and a little worried with so many thoughts rushing around in my head, I came to Eleanor's home. We found her in the kitchen with Giuliana. We said our goodbyes and talked of plans for the future, and then the time came to move off to the station. Eleanor looked at me thoughtfully, perhaps guessing the causes of my unusual worried looks. Sometimes she'd seen me very energetic in giving orders to my children to sit down and keep quiet while in the car. She sat next to me and asked very seriously, "Nunzia, are you angry?" It was time to get moving.

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I got up to say goodbye when I saw a flash of some sort of resolution in her beautiful blue eyes. She went to the drawer of the desk, took out a little sack of hers and opened it. It contained brightly coloured, very finely made marzipan fruits. She took one, put it down, cut me a little bit and gave it me saying "It's yours!" in the way a loving mother would use to rouse a sad child. I knew how difficult it was for her to give things to others. You couldn't speak about preparing birthday presents or things that were for other members of the family without making her angry. Sometimes she wouldn't allow her brother, whom she loved greatly, to taste with her certain things like ice cream or Easter eggs. Bernard prepared the food on the days when Giuliana went to university and Eleanor had certainly picked up her father's hearty eating habits. Just the thought of certain tastes could really get her moving. I remember one morning when she was very lazy and didn't want to get out of bed. She pretended not to hear my call to do things I knew she liked. I played a few tunes on the flute but she kept her eyes closed. So I proposed that we go on a visit to Furlo where there's a trattoria where she went with the family to eat mushroom and truffle tarts. Pronouncing the word worked like magic and in a jiffy she was awake and ready to put on her shoes.

Giuliana had explained to me how important it was to let Eleanor do as many things by herself as possible: washing her face, brushing her teeth, combing her hair and dressing and undressing herself. These exercises made her interact with her body and relate to the space around her and reflect on things. When she looked in a mirror or touched her feet she was conscious of her own form and its limits. She lived in given moments and bit by bit developed the personality that was hers. The work that Giuliana had chosen to do in educating her in a happy, interactive, constructive life was to follow her in the necessary therapy and the school work with the help of good doctors, patient teachers and many friends in order that she might confront the life around her as autonomously as possible. I remember an afternoon at the end of June in which we had picked the little yellow flowers of St John's Wort for the preparation of the essence. In that period Eleanor knew how to form, using an Italian ABC, the letters which made the right words and when Giuliana asked me to take a book down to understand a bit more about the characteristics of the plant and I had put it on the table, Eleanor took it with her usual determination and after having recognised the letter of the title, read the words 'Herb Book'. We were all amazed. She knew English and with her English father she preferred to

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(Eleanor with Coca Cola)

communicate with him in correct English. She didn't like illustrated books or story readings from books and didn't even sit in front of the TV. She'd get up immediately, saying "I'm not interested." But she had a passion for photographs and was able to reconstruct memories: she recognised the family members, her parents, the friends who were much younger than when I knew them and even the dogs who accompanied us on our walks. Occasionally she'd ask Bernard where Coca-Cola, one of her favourite dogs, was and when she was told the story of the friendly dog which, missing for a few days, returned to the house to die, perhaps poisoned, on the landing of the outside stairs, Eleanor withdrew into her own thoughts. On one occasion she'd amuse herself remembering the misadventures that happened to cars that the family owned and informed us of the details of the "crash", repeating the exhilarating sound over and over again. Winter passed and on our return from India, a little bit earlier in May, we found Eleanor

a little fatter. "She eats like a little bull!" Giuliana wrote in a letter full of enthusiasm, vitality and ideas. The young Venetian student was getting ready to leave and the family had got in contact with a Ukrainian lady who wanted to work in Italy but time was needed for the various immigration formalities and so I recommenced my working with Eleanor. That summer brought new experiences for us. We often went on little car trips to towns to have a walk around and take a snack, and we did some shopping too. Occasionally I'd take her to my home and we walked around to see all our dogs, cats and hens. In the house we put the clothes of my children more in order and moved the winter clothes in the wardrobe so as to make space for the lighter summer clothes. Eleanor liked this work a lot: an old T-shirt or a ragged old rucksack often attracted her attention and was able to mean something to her after Giuliana had given 'permission' to do the work. These were joyous afternoons and Eleanor was always eager to go out. She asked about the gears of my car, sat next to me, fixed her safety belt and sat happily watching the world go by. She recognised different cars: "Nunzia, Buy a Porsche!" she suggested. She didn't ignore her peers and stopped to recognise those who had a bizarre hairdo or dressed



in eccentric clothes. She knew how to move in the small shops just as in the great stores full of everything you could want. Perhaps the most difficult moment was that of going out after the things had been bought because the seductive power material things have over us doesn't always exhaust itself once we gain possession of a thing. The benefit often disappears quickly and you begin to feel dissatisfied. One day we found ourselves at the checkout of a hypermarket in Pesaro and after having paid for an orange haversack we noticed a fault in the stitching of a strap. It didn't stop the haversack being used, it could be closed OK and it was the last in that colour and size and it had taken time and patience to find it. I tried to reassure Eleanor who had become impatient and didn't know whether to take the new acquisition joyfully or return home empty-handed. You needed a lot of patience to calm her and in the end we decided to return home with the haversack, but for the whole journey Eleanor remained silent and unhappy. Once home she dropped the haversack in a corner and it didn't interest her any more – something that often happened with her new acquisitions. The way she expressed her wish to replace something was to recognise that the object was old. An excellent way of calming the impact of those moments when she arrived in the kitchen with shoes or clothes which she said were old or worn out was to write a list of those things that were useful to her. Giuliana took a sheet of paper and a pen, asked her to sit next to her, looked at the condition the things were in that according to Eleanor had become no longer serviceable and started to compile a list of the things which were absolutely necessary. She then stuck the list on the kitchen notice board to attest the agreement made. In this way you could save the elegance and utility of something that could still be used. When things were bought they were crossed out on the list and when Eleanor forgot that she'd a short time ago wanted certain things, the updated sheet was enough to calm her thoughts. She was comforted by the thought that she was being well taken care of. In the many afternoons we were together there was never any disagreement between us. Sometimes, seated on a bench outside, we didn't speak and I happened to note in her an 'absence', a distance such as that felt when you are deeply taken up with your own thoughts, but the slightest move recalled her to herself, the smallest call to react brought her back to the communion between us. The afternoon after a short trip in the neighbourhood she had forgotten to go to the lavatory before getting in the car. We'd driven for some hours and when she got out at home her seat in the car was wet. I tried to minimize what had happened saying there

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was no problem and that with a bit of water it could be cleaned and the heat of the day would soon dry the seat, but Eleanor got angry and for different reasons: not happy with what had happened to the seat but probably not agreeing with the minimum telling-off or any kind of joke at the expense of her abilities. She stood at a certain distance from me, crying and swearing. I remained still, looking at her as calmly as possible and suddenly she turned and went towards the kitchen, took a big and very wet sponge and cleaned the area energetically. This move to action made her feel better, less angry and more disposed to accept my thanks and compliments for having resolved the situation so well. Another time, at the exit of a small grocer's where we'd gone to do some shopping, she fainted, falling with her head coming to rest near little baskets of fruit that were behind us. It was a strong attack, happening in a fraction of a second and I knew it could recur at any time. Giuliana had spoken to me about these attacks that had struck Eleanor down once at the entrance to school where, in falling, she broke a tooth, while at other times some bruises on her body showed the results of this kind of fall in which the body lacked all vital energies. Bernard had ordered from the USA through the internet a red protective helmet which she put on before going out. Many people remember her as that very courageous girl with the red helmet. The warning symptoms of this kind of fainting attack couldn't be defined precisely and although Giuliana from the very first signs of the attacks many years before had taken care to observe carefully Eleanor's state of health, her feelings, her food and the daily happenings of her life, she was still unable to come to a definite conclusion as to the causes. The attacks happened just like that, like a bolt from the blue, independent of other things. These fits seemed, to medical opinion, like groupings and they certainly laid Eleanor low, travelling through her body from head to toe and leaving her exhausted. Only a therapy carefully followed over years could confront at least the seriousness and frequency of the attacks. Eleanor took drugs daily put inside little wafers in order to help the process of swallowing, which for her was a complicated movement. Almost all of her bodily features were normal: she had a beautiful face and she was tall. Her intelligence was active and reacted to outside stimulation. Sometimes I happened to unfasten the shoes and bent in front of her. I felt her hand on my head in a great gesture of affection, accompanied by the words "Nunzia, you're not a blockhead!" She had developed a strong personality and the colour of her hair together with her free

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(Photoportrait of Eleanor)

and easy gestures and language seemed to underline her Anglo-Saxon origins. I found our meetings very interesting and I thought about them before I went to bed or prepared new ideas for the following days. That summer Eleanor and Giuliana met me in the Grigne Mountains above Lake Como and with my parents we passed many happy days taking walks in the mountain pastures, eating and singing. One evening Eleanor danced around the table to the

rhythms of our song and after having gyrated joyously she noticed the watch my father had put on the sideboard that evening to signal the end of his daily activities. She took it with great attention and put it in his hands. Giuliana often used to give Eleanor her own watch when she wanted to remember something important to do or when she wanted to show Eleanor her total trust in her. When we'd returned home one afternoon she asked me if I knew her mother. I replied "Yes, she's called Giuliana. She's as tall as this, with hair that's a bit black and a bit grey. And do you know my mother?" She gave little jumps and smiled and together we remembered the adventures of that holiday time. One fine afternoon at the end of summer Galyna Shchygoleva, a pleasant Ukrainian lady, arrived. All the formalities of the job were explained to her. Her understanding of Italian wasn't perfect but Galyna was an educated woman with a lot of professional experience and gifted with an uncommon artistic sensibility. That evening she cooked for all of us some apple fritters that she was used to making at home and even though they were without the sour cream, which is not used in Italian cooking, we were all delighted by her ability. She had a past that was rich with experiences: she had been a nurse for many years and looked after her own family and her parents in their old age. She could sew and embroider very well. Her suitcases, jackets and hats were made and embroidered by her as were some beautiful wall hangings. At that time her country had been struck by a devastating economic crisis and so she collaborated with her husband who was a fine and much appreciated artist in his country. Together they had created and set up

in the Ukraine and other parts of the world an extremely interesting performance in which the female life was shown by means of a succession of different images. Galyna dressed herself in clothes she had designed and made. There was the search for the right materials, the contrasting of the colours, the study of the weave of the cloth and the different, original embroideries, and the attention given to the shoes and hats needed to create in the spectators those particular ideas which were associated with and animated the female life cycle – the gaiety of youth, the power of love, the dedication of maternity and the awareness gained by work. Alia, as we preferred to call her, came to live in the home organising her time with the activities she did with Eleanor: the creation of a new wall hanging which she would call Jerusalem in memory of a journey that had taken her there at an earlier time, cooking nutritious food and taking care of the animals that lived around the house. She had a preference for cats and told us the story of a blind cat which lived for many years in her house in the Ukraine.

I moved with all the family to Pesaro where our children had started their new school year and from there I came two days a week to Urbino, passed the mornings with the mother of a friend who was afflicted with Alzheimer's disease and had closed herself up in her own world where she forgot the existence of organised life. I gave the afternoons to Eleanor. In her school exercise books I found a lot of finely drawn designs, arabesques and decorations which took my thoughts back to the Orient where the world is thought of and represented in art in such different ways to ours. A new spring arrived and Eleanor continued at her school. Alia had improved her understanding of the Italian language a lot and had widened her circle of friends thanks to Giuliana. I had started a new job at Easter as a kitchen help in a restaurant in Porto Verde run by the son of a friend of mine. I worked on the evening shift, reached the restaurant in the late afternoon and prepared the vegetables, some flat bread with rosemary and the desserts. One evening I invited my friends and prepared fried bread savouries with capers and anchovies which Eleanor loved. It was a wonderful evening and sitting under the porticos on the bank of the *river canal* we talked of many things and agreed to meet at Giuliana's house a little later to celebrate Giuliana's birthday. I prepared a sweet covered with a chocolate glaze and Alia a short pastry filled with cooked lemons, a recipe she'd learnt from her grandmother. The school year came to an end and we left the flat in Pesaro to return to our house in the country. Eleanor loved going there

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and was even happier if she found a boy there. Sometimes Pier Paolo passed the afternoon with us and he never forgot to ask her if she knew the name of her grandfather. Eleanor, who had a good memory, said the name correctly, pronouncing the sound of the first syllable in a particular way, stretching it so that it gave a sound full of affection for him. Autumn brought the beginning of the school term and we transferred Pier Paolo to a middle school in Urbino because the school that was annexed to the conservatoire had been closed and he'd be able to follow his studies in the violin in Urbino, while the other pupils were able to continue their studies in Pesaro. I finished my work at the restaurant which, after a very wet summer, found itself in difficulty. In November I was called to be a supply teacher in the Istituto Ruffilli in Forlì. Eleanor and Galyna started a course of music and dance in San Bernardino. One afternoon a group of disabled persons, organised in an association by Father Adriano, a monk of the Franciscan order, met a kind German musician, our friend, who taught music and dance to people of all ages and abilities, in order to get an entertainment ready for the Christmas festivities with songs, dances and a little show. They learned simple musical motifs, played various instruments, in a group or individually, studied the movements and styles of simple dances – which once performed made them short of breath but brought a lot of pleasure – and the group didn't break up before they'd had an afternoon snack together. Sometimes I acted as a substitute for Alia and formed part of the group. It was amusing to sing, at home, some of the songs or recite some of the words of the show together with Eleanor: "Fiocco! Fiocco!" shouted the shepherd in search of his lost sheep. It needed only those two words to make Eleanor merry. The end of the year festivities were near and we spoke attentively about the presents and happily about the good food and we made a lot of biscuits together. Alia was now at home with everybody and looked for new work possibilities but it was difficult for her to get to the town using the buses and she started to think about a change in her base. In that period Eleanor was very uneasy, swearing or kicking those whom she considered the source of her dissatisfaction. I remember one morning at the market with Bernard and Alia when choosing a sportswear garment had created difficulties for Eleanor because the one she liked wasn't the right size and she had to leave it at the counter in order to continue looking. She became very impatient and it wasn't easy to calm her down. We bought a very nice olive green piece which, even if a little bit big for her measurements, didn't calm her and once

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we'd arrived home Bernard sent her to lie down. Eleanor had a monotonous diet, in the sense that she always and only wanted to eat a mix of bread with olive paste and the crushed anchovies or capers normally used to fill baked tomatoes.

We prepared a good plateful for her and sometimes tried to enrich it with boiled fish or other flavourings.

At school she passed many hours stretched out on a camp bed because she'd suffered an attack or because she didn't want to stay in class. In that period she studied Manzoni's *The Betrothed*. I saw the class exercises she did in which she had to choose between two possibilities in questions about the characters of the novel. The supply teacher who taught her that year was very happy with her progress. One afternoon I went to Pesaro with them and another supply teacher to meet an expert in facilitated communication. We were shown how, by associating on a long, narrow poster the part of a sentence printed in small italics on the one side with an image printed on the back, it was possible to stimulate the visual memory of a person with learning problems so as to make them remember at first short phrases and then, by repetition and keeping the connection to the image, longer phrases and with time and practice complete paragraphs. The most interesting thing about this method is that starting with the copying of simple phrases you can increase the ability to write them on your own without the need to copy them from the back of the poster, and so understand the alphabet and its use. I have to say we were all most attentive to the demonstration and explanation of this fantastic method. Eleanor was calm and seemed to listen with interest. When we'd left she became excited looking in a shoe-shop window. When we arrived home Giuliana asked her how the day had gone. She started to puff and snort, perhaps to express her boredom. In fact she had little interest in the alphabet and words.

The festivities of the end of the year came and we started to decorate the house and the Christmas tree. We celebrated with songs, dances, bingo, gifts, food and the great joy of meeting with the many friends. After a month I decided to stop the supply teaching in Forlì and took up the duties of a housewife and mother, both of which I had been able to devote very little time to. Alia found a new, interesting job in Pesaro and decided to leave the Worthingtons. When she'd left, Giuliana was happy to accept my offer to work with Eleanor and we started immediately with a timetable which meant I spent two nights a week there. I was able to help Eleanor get ready for school in the mornings when Giuliana was in Pescara.

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Now, when she woke up she took longer than usual to get out of bed and I needed to give her a hand to get seated. Sometimes she had difficulties coming down the stairs from her bedroom, still painted with Galyna's roses. Giuliana had shown her how to come down the stairs by sitting on the steps and Bernard helped her in the evenings to go upstairs. One Saturday, when we'd decided to go to the market to buy a pair of shoes, I was awakened by a thump. It was very early morning but perhaps Eleanor had decided to get up on her own and had thought of coming to me in the bedroom next to hers where I slept. I found that she'd fainted and was lying on the ground near the door on the rug of the little corridor. I picked her up and put her in her bed. When she'd recovered from the attack I brought her a cup of ice cream and helped her to wash and dress. We came down the stairs together and accompanied Bernard to the market. Swallowing food in that period was certainly a very complex operation for Eleanor, as was expelling the phlegm resulting from a cough or cold. The only thing she managed to swallow was a cup of Soya ice cream with some cereal flakes. We'd tried to stimulate her to spit or blow her nose but she couldn't and her breathing was shorter. When an attack came now it made her lips tighten over her teeth and they became violet and were cut. Giuliana wanted to have the teeth moved in such a way that they didn't cut the lips. She covered Eleanor with her arms to give her the warmth of her love and the courage of her understanding. A doctor was called and he suggested that Eleanor be fed liquid and food by means of a permanent drip. The phlegm however made respiration difficult and the lack of oxygen brought on more attacks. During the night an ambulance came; from Urbino she was sent to the intensive care unit in Ancona, Urbino had not a spare bed for her. Bernard, Giuliana and I remained in the corridor and then the parents replied to all the doctor's questions but it wasn't easy to create a complete picture of her health problems. Many aspects of her body's functioning and other pathological factors remained almost a complete mystery. In Ancona pneumonia was diagnosed but the great difficulty she had in breathing meant that she had to be taken into the intensive care unit. When we were outside the ward after having spoken to the doctors, Giuliana took out a big folder containing all Eleanor's clinical documentation, which we were waiting to see. That day Giuliana let me go in first to see Eleanor. She and Bernard stayed in Ancona for all the time necessary. I went along the corridor which seemed like a kind of bridge and opened the door that led to the room where Eleanor

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was now sleeping. She breathed using oxygen supplied from a mask over her mouth. I tried not to allow myself to become overwhelmed emotionally. I took her hand, so small in comparison with mine, and stroked it tenderly, almost without touching it and started to talk to her. I told her who I was, where we were, where her mother and father were and that everyone was thinking of her in those difficult moments with great love and that the strength of her spirit and her great courage gave us a great consolation. "We are all proud of you! You're a sensible girl! Our Eleanor is so able to do different things!" I said this to her before I left. The bronchitis was cured and she could return to Urbino but the periods in hospital continued and the breathing difficulties were overcome with a tracheotomy. One afternoon I went to see her and I took with me a big chocolate Easter egg.

This time she was awake and as soon as she saw it she wanted to hold it, with the decision in her gesture and looks that I knew very well. I was relieved and happy at this reaction and by the particular smile and the attention she gave to my words when I was leaving. I told Giuliana who wanted my opinion. The days passed and her condition remained the same.

The vital force seemed to have left her body which remained stretched out on the bed in the room next to the reanimation unit. She was washed, freshened up, fed, and all the nurses treated her with a particular care and always found particular words to encourage her and make her smile. The little tube that came from her throat had to be kept clean – it carried away the phlegm that sometimes made it difficult for her to breathe.

Giuliana was happy with the improvements but the time she could spend with her was so little! I wondered if she'd consider it a good idea to take Eleanor home, to her usual family home with all the sounds she knew, the daily bustle and the noises of the animals outside. We would learn how to manage her equipment, would watch her constantly and the consultant was in agreement with the idea. The following afternoon we learnt from a nurse how to use the pump that regulated the flow of food, how to clean

the little respiratory tubes, how to remove the phlegm and how to change her bed sheets. She was given a room on the ground floor of her home. These were tense days.

We alternated our vigil sitting on a chair by her bed, speaking to her, encouraging her in the more dramatic moments in which the increasing number of attacks overlapped with other difficulties. By singing little songs we brought a smile to her lips. The consultant came to visit, Father Adriano brought his prayers, some friends came more regularly and my children

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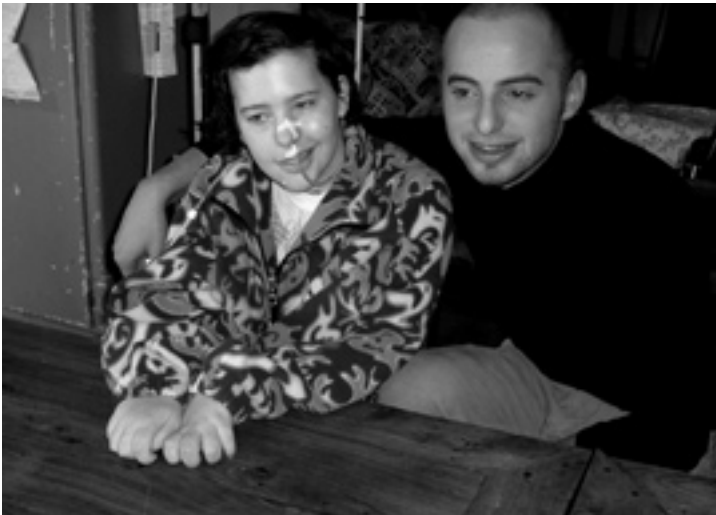
came too. Pier Paolo had some memorable dreams in which he said he saw Eleanor's house near a beautiful beach washed by a calm, clear, welcoming, turquoise-coloured sea. Many friends were there and passed their time on the fine sand writing poetry which, we didn't know how, formed these words: "Drips a drop of water/ There where there isn't water/ It doesn't have a smell, has a good taste/ Hours, hours, there's also love waiting/ Love and friendship wait for that smell/ Which before the first rains arrives / When you reach Life at the bank / There where time doesn't flow / The memory of pain doesn't run." We were all touched, waiting. They were unforgettable days and our energies were put to the test. Giuliana started to look for people who could collaborate in the daily and nightly help. The home nurse came every morning to cure some of the bedsores which had formed on Eleanor's feet, until one day Dr. Martinelli allowed us to allow her to sit up a little in bed. Dr. Vitali, the neurologist who had followed her for many years, adjusted the therapy appropriately so that the frequency of the attacks was noticeably reduced. When he paid a visit he told us that Eleanor's vital energy was enormous, that she wanted to live! Her blue eyes started to get used to the environment around her and she looked at us. The noises of the house gave a rhythm to the days and perhaps resounded in her ears. She didn't speak, nor did she manage to keep her head erect. We made her sit for a while on the bed, holding her and massaging her back and shoulders while chattering about many things and singing. Then from the bed we moved her to the wheelchair and finally one day we came out of the room.



(Eleanor smiling)

We started to take her into the kitchen and little by little outside the house, underneath the mulberry tree where the cats, hens and geese attracted, as always, her attention and made her smile. One fine day we got news of a young man taking a degree in Psychology had agreed to do his military service as a conscientious objector in Urbino where he was studying. He had been assigned to do a number of hours each morning helping Eleanor. Now she was passing

an hour or so outside. We made her put on short pants and a T-shirt which allowed her to take the air and the sun on her very white skin. With patient exercise and her active collaboration we had managed to make her breathe through the mouth. Now we needed lots of napkins to wipe off the dribble that she was unable to swallow, and a container for them. The small hole at the front of her neck started to close after Dr. Martinelli removed the little tube from the windpipe which had allowed her to breathe better. Francesco arrived to fill Eleanor's mornings with his presence, delicacy and love. Between them a closeness of thought began immediately, a friendship so extraordinary and intense that we could hear the joyous gurgles of her laughter when a word of his or one of his special looks reached her. He called her "signorina" and she greatly enjoyed his company and looked forward happily to the next day.



(Eleanor and Francesco)

Together with the laughter came tears too. One day Giuliana was talking to a friend about a sad happening and Eleanor, who was sitting next to her, started to cry. This convinced us that her ability to understand such things had slowly but surely found its course. I spent the afternoons with her and woke her to start the pump that regulated the flow of liquid food, cleaned the tube with a water syringe, dressed her in her trousers, put her on the bed, stroked her gently

and massaged her legs, which I bent to suggest the muscle positions for standing. When she was seated with her legs outside the bed there were exercises with the arms necessary to make her put on the T-shirt and jacket. We talked all the time this was going on of daily events, accompanied by a flow of questions and intuiting or anticipating replies when her smiles weren't sufficiently eloquent. Then with Bernard's help we put her in the wheelchair and I opened the doors of the wardrobe where there was a mirror. While she looked at the world from there I washed her face and combed her hair or made a pigtail taking care that the elastic didn't pull the hair. We carried out some oral hygiene using gauze moistened

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with mouthwash and then we both went into the kitchen. Seated near Eleanor I started colouring some drawings in drawing books printed in black and white which had been given her as a present. If I found a cow or a cockerel I told her adventures we both knew about the animals of our house as we put in the colours. Once, using coloured crayons, I drew the cats which stayed leaning on the glass door of the kitchen and wrote the name of each of them next to their drawing. We thought of sending them to Martin who sent us lots of postcards from the places he found himself in. We coloured and read together the cards, grandmother Marie from England drew for her showing cats and puppies of all types, and which always started with “My little sweetheart.” I played a flute or a xylophone and sang simple tunes and started to do watercolours. I was fascinated by the colours which the seasons gave to the vegetation of the hills I came through, particularly on the secondary roads where the trees and bushes of the sides were nearer. I thought of capturing this impulse of the seasons in my watercolours, this extraordinary ability of the vegetable world to interpret the influence of the sky, each day so different, so new yet the same, able to offer us almost imperceptible variations: the violets flowering in abundance, filling their leaves with a deep blue – violet colour which is testimony to the abundance of water which has restored everything. There the exploding yellow of the mimosa recalled the warmth of the thousands of little stars, and the perfectly transparent petals of the poppy could be caught on paper with a single brushstroke. They would be dried in paper and that perhaps helped Eleanor to understand the mechanisms that carried the liquids that transformed themselves. In Eleanor’s food we started to introduce, in alternation with the Soya-based ingredients perfectly balanced according to nutritional requirements, fresh food liquefied in a food mixer: beakers of fruits and vegetables of the season, milk of almonds, and vegetable paste with a small piece of edible algae, well cooked and carefully filtered and passed again through a fine mesh. The food, in order to reach the stomach, had to pass through the tiny hole at the end of the little probe. Keeping this little tube open, working and in the same position from the nose to her shoulders wasn’t always easy. Sometimes it closed, blocked by food; on other occasions her fingers, which sometimes made involuntary contractions, pulled out the tube. The nurse who came to replace it was very capable but the discomfort that the procedure caused Eleanor made her cry. Life continued for those of us who were nearest to her and after having

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confronted and overcome so many difficulties, Giuliana would say “We’re on the front line!” on the days with particular problems. The quiet presence of Eleanor, her participation in the happenings, the joy she found again seemed like a gift and kept us going in our support. When blood and urine tests were taken we were all surprised at the excellent results. The neurologist, who gave us important advice, encouraged us to publish the observations we had made as his other patients rarely did. We were able to keep Eleanor’s bowel movements constant with the use of certain drugs and everyone was satisfied. Then she was washed with a sponge and sometimes massaged with oil. After having dressed her in a clean T-shirt and a large pad we opened the wardrobe and showed her all her clothes. The racks were full of clothing, all put in order by the people who assisted her. From a smiling look I recognised which one she had chosen for the day.



(A portrait of Eleanor)

A physiotherapist came two days a week to treat her. There were exercises in flexing the muscles, rotation and extension of the arms, hands, the legs and the feet. At the start she was stretched out on the bed and then put in a normal chair. The muscles of the neck and shoulders started to strengthen and now she was able to keep her head more upright and look forwards. Each movement she made was done as a rehabilitative exercise. There were also

those exercises using a ball: she was seated with her back to the physiotherapist and tried to catch and throw a ball that was thrown to her.

She made good progress. Once we saw her raise her arm by herself in an aggressive gesture, almost an attempt to scratch the person in front of her, and as such always a means of expressing strong discomfort. Giuliana bought a motor vehicle with a moving floor step which allowed the wheelchair to be raised and lowered. There were straps to hold it in the centre. It was easy to use and worked almost every time. In her ‘silver’ car she started to explore the movement of the world outside. When driving you needed to look out

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in particular for holes in the road. The non-tarmac roads, like those near the house, had to be taken very slowly so that Eleanor's body wasn't hit against the sides of the head rest. One memorable day the track that ran from the main road to Eleanor's home was completely resurfaced with tarmac on its main stretch and with gravel on the short section that went down to the house. A neighbour had made a request for the work many years before and to the joy of all concerned the request was accepted. In San Bernardino the dance and music lessons started up again. We went to San Bernardino where we could meet the old friends with whom we could play, sing and dance. At first Bernard came with us, and we were all welcomed with great affection. Everyone wanted to look after Eleanor and give her lots of kisses, caresses and particular attention. All happened, as we know, in accordance with everyone expressing their own characteristics according to the characteristics of the sky on that particular day! We stayed for tea so that Eleanor could have a teaspoon of orange juice or have a sip of whipped cream. Only the taste buds could say anything in effect but it seemed to us important to stimulate the movement of the tongue. When Alfredo went to visit her I invited her to make "Linguaccia" and sometimes

(The hat of fire)



she did manage it and it was a great satisfaction and joy for him too.

After the end of the year festivities Ulrike thought of setting up with the young people of three groups belonging to the centre for the disabled in Urbino and Fermignano, a theatrical show entitled Earth, Air, Water, Fire. We started going to the morning sessions of the rehearsals in the Posto delle Viole of Fermignano. Many young people of the Francesca Centre were there accompanied by their teachers and there was also the VASIS group from San Bernardino. Ulrike knew all the people who worked together. She'd known them for many years and used her ability and artistic sensibility as a music therapist. There were many people of different sexes, ages and with different disabilities, some like Eleanor in wheelchairs, others younger than her and full of enthusiasm, but all were very nice people, curious about life and with a gift of spontaneity and showing reciprocal and authentic tenderness. And so our circle of friends grew considerably.

We started off from home with the food to share out and everything that was needed to allow the two hours to pass without interruptions. We learned our parts, chatted with the others and were fascinated by all the new things, the parties and the many activities organized by these young people, the loving kindness that grew between us and the people who came and went. Occasionally we met young, intelligent trainees who were a great help. Francesco had finished his two years of service and was allowed to return home to his family. He invited Giuliana and Eleanor to his degree party, which was near. The young Monia from Pallino took his place. She brought with her a joyous view of the world and a high voice, and they were both highly appreciated. The music, poetry and dance show was put on before the summer in the Urbino theatre. It was a success. Eleanor in her chair on the stage represented Air. Some silver-grey material was draped over her trousers and black vest; a blue cardboard two-pointed hat was decorated with long ostrich, pheasant and hawk feathers which moved with every movement of her head. In the afternoon activities we'd prepared together the hat for the Elements using two shapes found in the kitchen, one long, one short, and we coloured them and then glued on red bags with tongues of fire

(Francesco's Degree day)



to represent the element on the tall one and added many red touches here and there. Over the open short one which opened like a little blue crown, we put ribbons of sky-blue satin which came down smoothly and in parallel to represent Water. We had great fun making these and the afternoon before the performance we wove flowers, green twigs and bunches of wisteria in a crown to represent Earth. The four elements in the corners of the stage were very beautiful; the costumes prepared by the teachers of Posto delle Viole for all the players were impeccable and the lighting effects, choreography and music which accompanied each scene were perfectly timed. Father Adriano read the pieces chosen to introduce the characteristics of each element while the actors, like true professionals, changed costumes and silently got ready to enter on cue. The show was repeated in Urbania and the following year we were ready for another on Polarity, a new and very interesting creation. Carla, a frank, energetic and very affectionate woman who took part, said to



(Performance poster)

me with great seriousness every time the curtain came down, “Nunzia, we are actors!” I couldn’t disagree. We all congratulated ourselves and collaborated with great interest in Ulrike’s project.

We got to know Ingrid, a thoughtful and kind mother, who spent some hours with Eleanor. Now that Giuliana had taken up her work again at the university and she had to spend those nights in Pescara, a smart lady of Urbino, Oriella, who had known the family for some twenty years as a neighbour, helped in those periods. ‘Little sparrow’ or ‘Little witch’ are the epithets most used by the mothers of the Urbino area for their little children and many normal gestures used with Eleanor came from the particular maternal sentiments expressed in that area. But, in effect, Eleanor had become big now; she’d matured in her experience and was a young woman. “There aren’t any little babies here” Giuliana used to say. “Today Eleanor gave me her gloves and jacket with a quiet smile and was very contented doing it.” Sometimes she’d sleep at our house and seemed

to feel at home, sharing with our children that particular complicity of feeling and language which characterises the new generation. It made her laugh and she responded to that stimulus. We’d stimulated our own young children to reflect on life, its various aspects and significance and they made a place for her among them as if she were a sister. One afternoon she spoke the letters of some words relating to a rucksack which we were going to buy. ‘New,’ she said, and when Giuliana was sitting next to her in the evening she heard ‘Mummy’. We had tried earlier to stimulate her ability to speak. Giuliana spelled out the first word that she had pronounced and I repeated other meanings for her memory to take up. We immediately found that this exercise represented an enormous effort for her. The attacks, that were at that time less frequent, seemed to increase. A small adjustment in the dose of therapy was made and brought calm and also some expressive abilities that she’d learnt to use. It’s not easy to get a living equilibrium when there are obvious disadvantages on one side. However, individual experience is a unique condition for which there is no substitute. Sometimes the investigations into our precious life bring us to an understanding of impotence and unhappiness in that we are

quick to attribute our own imaginings to others. We forget that those imaginings are an exclusive part, useful for a single individual. The known differences between individuals shouldn't be perceived only as forms of inability which bring a sense of blame and isolation; they can be a stimulus to understand the much-used but complex concept of equality between human beings in the multiplicity of forms that is a fundamental of the human race.

A world full of friends, interests and activity circled this young woman. She passed the winter without catching influenza and had a dental operation as a rather large cyst had formed in a tooth producing infection and a lot of pain. In the hospital in Cesena she bore all with the usual courage that touched us all. She went fearlessly into the operating room as Giuliana had explained what was going to happen there. The rucksack was prepared for the departure and Giuliana waited outside with Bernard and me. Eleanor came out in an hour to the smiles of her loving parents who patiently looked after her like two angels that had materialised there. When she asked me, for the first time, one quiet afternoon when we were seated together "Nunzia, when will you die?" I was shocked, but tried to reply immediately and not leaving a too long period of silence. In fact I'd already asked myself that question and didn't want to express the usual unease that this question conjures up. "When I'm really old, my little darling. Like the grandma of Edoardo, Valerio, Alfredo and Pierpaolo who gave us sweets when we went to visit her." I remember the poem of Lina Schwartz in which the grandfather, bent, white and tired, is walking over a meadow holding her merry little nephew with his curly blond hair. "I'll soon be going away, far away, and I won't return," he said to him and the child replied, "No, grand father! I'll write to you!" Perhaps the meeting with the people we come into contact with in our life's journey is in some way independent of our actual will, but we notice, in using the memory, the enormous quantity of wisdom that this meeting contains. We learn to recognise ourselves, to grow in the experience of life, comparing ourselves continually with other human beings and we are stimulated by the dedication we use regarding them. Learning these things makes those aspects of our personality emerge which we recognise as the most valid givers of happiness. If aims exist to whose realisation our way of living and acting is turned, they are those which distinguish our diversity. This is our contribution offered to the world in order that the human race is perpetuated in a continuous evolution. What an enormous task! What strength of spirit! What an unrepeatable period of time was given to all of us in knowing Eleanor.

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CHILDHOOD

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# UNCLE LUIGI'S MEMORIES

When you were in Genoa I was too busy with my job to pay much attention to children, let alone those of others and of my sister! I do remember however, an episode, or a flash, and I'm not sure why, but most certainly as a joke, I threw some water on her, I can't remember if it was some water left in the bottom of a glass, or with the garden hose: after a moment of bewilderment, she fixed me with her gaze, blazing, not with anger but with boundless resentment: which in the eyes of a young girl only a couple of years old, had the same effect as a punch on the nose.

After she left Genoa, I never went to visit her, I think out of cowardice, because I wanted to remember, as I do remember, two bright and beautiful eyes, full of curiosity for the life that was unfolding in front of her and that we all wish had been more generous to her.

(Eleanor in Montesoffio)

God has given,  
God has taken away;  
Blessed is  
the Name of the Lord.



# AUNT CHELLINA'S REMEMBRANCE

It is very difficult to talk about Eleanor.

Eleanor was a girl who from her face, her expressive eyes, and body was brimming over with joy, she also had a mischievous element and she made you join in with her hilarity. I don't remember Eleanor angry or sullen.

I have a very vivid memory of Eleanor, and when I think of her, she immediately comes to mind as she was in that moment. I don't remember her precise age but she was about three of four years old. She was blond, curly hair, the bluest of blue eyes and a very mischievous air also because a dimple appeared when she smiled.

We were in the kitchen in Genoa which had a large central table. Eleanor, probably tired of my anecdotes began running around the table, laughing, and I was chasing after her. At a certain moment, still laughing, she changed direction, slipping through my legs. She was playing and I couldn't catch her, she ran even faster, laughing as if to say 'Got you.'

She was very graceful and agile and she seemed to me like a butterfly happy to be quicker and more alert than I was, and when she turned round to see how far away from her I was, her blue eyes shone with contentment.

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## AN IMAGE FROM MARGHERITA

Of you Eleanor, I have only one image  
Of a blond child who jumped up and down on the balcony  
And at the edge of the sea in Genoa.  
Life  
Oh my inability of give order to life  
Hasn't permitted me  
To know the grown person that you became  
But the extraordinary vehicle of love  
That you were and still are  
You were always felt and we still feel you  
Here in Albissola.

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SCHOOL

# A LETTER FROM GIGLIOLA

That cage was too restricting,  
and every day more oppressing.  
Like a butterfly that leaves it's Chrysalis  
and is free in the immense sky  
You too have left your cage  
And you have gone far away.

Dear Giuliana,

Your telephone call sent me back in time bringing back to mind memories that I thought were lost.

Eleanor was very ambitious; she habitually wore very comfortable track suits, but she loved clothes. I remember that one day she arrived at school with a new dress; she was very happy and wanted to show it to everyone. We visited all the classrooms and even the children and teachers at the nursery school. Everyone complimented her and she was so happy. It didn't take much to make her happy, a word of greeting, a smile or the attention of the people she loved.

She had a very unique way of showing her joy; she jumped up and down on the spot as if she had felt an emotion so strong she couldn't keep it inside! She showed her displeasure by harrumphing and wagging her finger in front of the person who had said or done something to cause her displeasure. She was precise regarding some rules, sometimes very punctilious. She liked to listen to stories, and when she wanted to listen, she would take the book directly from my bag and give it to me. When she didn't like the work we were doing, she would grumble, and to spite me, if I insisted on her working, she would make a sign to me on her hand with a felt pen, with a serious face. I would laugh and chased after her threatening to do the same thing. It always finished with laughter and then she would continue to work.

Sometimes after her seizures she would shake her head as if to say 'It's ok, nothing's happened', then she would continue the interrupted activity as if nothing had happened.

Eleanor, I think of you like this:  
As a soul closed in a cage.

# MARSINA'S NOSTALGIA

I remember with affection and nostalgia the period of teaching in the school at Montesoffio at the end of the 1980's.

A lot of time has passed, but I remember well the enthusiasm, the willingness to work and to work better which was at the heart of all the teachers in the little country school.

The arrival of Eleanor certainly 'shook up' a little the tranquillity of the school, we were used to organising a small number of pupils divided in five classes, but we weren't discouraged, in fact it was stimulating to understand how we could best help her to integrate progressively into our world. Everyone was involved, the pupils, teachers and the caretakers...

with the continuous discussions with her parents, we decided that the best way would be to involve as many children as possible with helping Eleanor, to help her feel better, so that she could live their new experiences in the most natural way possible. We were convinced then, as I still am, that 'diversity' can be lived as an enrichment, not as a limitation, but it isn't an easy challenge. Would Eleanor's companions be able to understand, grow peacefully and be aware of their growing sensitivity as daily they were able to compare Eleanor's 'diversity' to their own lives? Would we be capable of guiding them in that direction? Today, I know we succeeded.

Certainly it wasn't without some difficulty and some problems, but I understood that we were right some time afterwards, after a small but significant episode. At the end of that year, I was on maternity leave, after the Christmas holidays I went to see the children at school, and whilst we were talking, all of a sudden, Eleanor fainted. It all happened without the 'warning signals' which usually happened, and I was really frightened. Together with her teacher I tried to help her and support her, very worried about her condition. The children however, very calmly went to fetch the camp bed from the corner of the room which was available for such occurrences, they laid her on the bed and stayed close to her

(Eleanor's Birthday  
at Montesoffio school)



with such naturalness until she woke up. Her illness didn't frighten them nor kept them at a distance, on the contrary, she became part of their experiences and their lives and they dealt with it in the best possible way. When she woke up, Eleanor repaid us all with an unforgettable smile. I was very moved, I understood that she was teaching us so much, and with her difficulties she enriched our lives and gave us the strength

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and the courage to face challenges and the hardships imposed by her condition.

What makes me happy today, is the awareness of how much more maturity, sensitivity and life experience we shared, both pupils and teachers in that period lived together at the little country school of Montesoffio.

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## FROM RITA TO ELEANOR

One most certainly cannot say that life was generous to Eleanor, even with her sensitivity, freshness, joyfulness, she knew how to cope with such strength and serenity, leaving a profound mark in the hearts of people who were fortunate enough to know her and love her.

I like to remember you happy and smiling together with your friends, with your lively gaze, your blue eyes, mischievous and friendly which transmitted joy and happiness.

It makes me feel bad however to think of the suffering which crossed your path.

I would like to dedicate this poem to you and all the people who were around you to benefit from your joy and share the difficult moments with great love and dignity.

### THE JOY AND THE PAIN

#### On Joy and Sorrow

**Your joy is your sorrow unmasked.**

**And the selfsame well from which your laughter rises was**

**Oftentimes filled with your tears.**

**And how else can it be?**

**The deeper that sorrow carves into your being, the more joy you Can contain.**

**Is not the cup that holds your wine the very cup that was burned in The Potter's oven?**

**And is not the lute that soothes your spirit, the very wood that Was hollowed with knives?**

**When you are joyous, look deep into your heart and you shall Find it is only that which has given you sorrow that is giving you Joy.**

**When you are sorrowful look again in your heart, and you shall See that in truth you are weeping for that which has been your Delight.**

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**Some of you say, “Joy is greater than sorrow”, and others say,  
“Nay, sorrow is the greater.”  
But I say unto you, they are inseparable.  
Together they come, and when one sits, alone with you at your  
Board, remember that the other is asleep upon your bed.**

**(by Kahlil Gibran, The Prophet)**

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# A THOUGHT, A MEMORY FROM EMILIANA

A thought, a memory.

I knew I would find you in the classroom that day, and so I entered it before your class mates arrived. You were sitting at the back, next to a young woman who was talking to you. I introduced myself and you, after carefully listening to what I said, turning to your teacher, smiling and with a witty look, uttered some words in English, I can't remember whether of disappointment or of pleasure.

This was our first meeting.

You would always enjoy following lessons; you used to enjoy the topics dealt with, and when you did not, you would start singing, perhaps getting up from the desk, to your school mates applause, whom you were perhaps saving from some unpleasant situation...

You were very well settled in the class, everybody loved you, and you reciprocated with affection.

The medieval castle, Don Quixote and his wind mills, Romeo and Juliet, and then The Betrothed, which your mother used to read to you as well...and Pirandello, with his “six characters” which moved you while watching the video, to everybody's great surprise, because that day you cried.

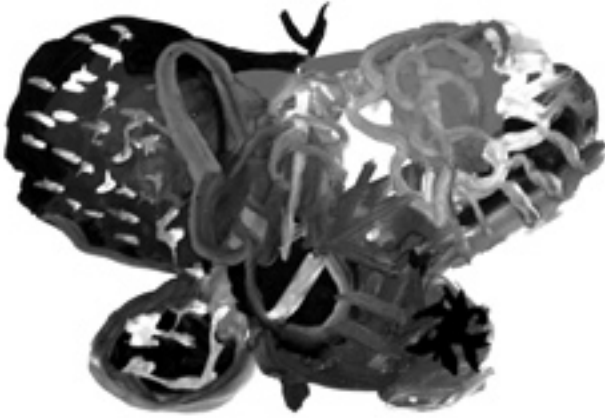
Yes, your feelings, your sensibility, your affection, the liking you were showing towards some of the boys, even though well disposed towards everybody.

In the last year not all of your fellow students were those of the first years, many had stopped early, some had preferred to leave school for work, but every day those who remained were waiting for you to arrive, visibly worried about your health and aware of your suffering.

The joyful atmosphere of the first years had gone, there was the worry of the final exam, perhaps a greater sense

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(A butterfly for Eleanor,  
drawn by Misha Shygolev)

of responsibility, but towards you I always noticed the same sympathy and concern as before.

My mind often goes back to those years which were so significant for me but also, I am sure, for those young people who grew up with you among those school desks, who I am certain will always remember you with affection, because at an age as difficult as adolescence, you undoubtedly brought them to reflect on the true values of life and on the deep meaning of existence.

Your teacher of literature.

## A POEM FROM FERRUCCIO

OUT OF TUNE  
(Nino Pedretti)

Since I was a child  
Shut up, don't sing  
You're tone deaf  
And they sang and sang  
Happy like larks  
Now I am grownup  
And I don't care about the others  
I sing too  
A grand voice along the road  
But what's that fool singing  
What is out of tune?  
Inside me  
I am a violin.

Maybe I never read Eleanor this poem, but I am sure she would have liked the ending.

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DAILY LIFE

from York and Genoa to Urbino

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# CONCETTA'S RHYMES

## A beginner's Verse

To Eleanor a beautiful child  
A child that runs, who is always jumping  
Then grows a little, and like a star  
A wounded star, we don't know why  
But you want to love her, always until  
You can give her love that you have  
Closed in your heart like a bonsai  
Then you think, you can help her a little  
And you can't find anyone who can understand  
You look here, and you look there  
For something that will help her to find serenity  
But time passes, and the years pass  
And this fools you  
All the ideas that you had  
About how to help her, you really don't know  
You ask yourself what you can do  
A thousand suggestions, all to be tried  
You have to accept life as it is  
But your joy you know what it is  
The joy to give everything you can  
To that child who has your eyes  
You bring the world to her  
And she digests it even if only a little  
She appreciates it, her sparkling eyes  
Cry and laugh with shiny cheeks  
And that smile for her mum  
Is joy itself, even if in this drama  
The months go by, and the years go by  
And we find her, with many ailments  
Like life, the joy she gives  
Not everyone experiences,  
Moving forward we are always looking for ways  
To help them, yes, we must  
They had our children with them for a brief time  
And we, there, always ready, with our advice  
Advice on how to accept life  
Which for them was more than a challenge  
We stand close to them, and we are with them  
To share a destiny  
A dreadful destiny, that we know  
Only love, will overcome it, you know.

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# A DINNER WITH PETER



(A portrait of Eleanor)

Let's begin at the beginning, which is with a wholly unexpected invitation from Bernard to go to dinner one evening at Giuliana's flat in Genova. I'd known Bernard, but only rather casually, as a colleague at the university and was rather caught short by the gesture. I remember Bernard and I were talking of some teaching business and then as a tag, he added as if casually offering a coffee in a bar, "Oh, by the way,

Peter, would you like to come to dinner, say ...?"

And he named a day. It was the kindly, unaffected gesture that caught me out. And when I went to the imposing palazzo I was welcomed in the bright, spacious kitchen by Giuliana, as energetic as ever. There was the little boy Martin, and Ellie who roared a welcome. We started the meal straight away and I immediately seemed drawn into the family as if I'd known them for years.

I noticed that Ellie was given no special attention other than that due to her handicap – she wasn't then physically disabled. As with her brother, if she did anything wrong she was reprimanded, and what she did in good faith was praised. Yes, no special attention was given – but I gave Ellie special attention as I ate my meal: a spoon or a plastic cup might come flying in my direction as Ellie "expressed" her disappointment or irritation at something. But all was treated as normal to the given situation and we ate our food together. Ellie was not separated from the family-dinner-plus-guest in any way. She was totally accepted, without any veneer of "polite" apologetic manners in front of the guest which could hide resignation or a gnawing regret. She was an equal to Martin, 'differently able,' and Giuliana wanted to bring out all the positive aspects of that diversity which wasn't, clearly, to be the one of academic success that Ellie's brother would enjoy. However – and this I thought

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important too when I learned of it – Giuliana insisted that Ellie go to an ordinary Italian state school and have a pagella at the end of term as all other pupils had.

But this was later ...

So I ate my meal with a little trepidation. But I was invited back to eat many meals and to spend Christmas in the Cella di Pietra house when the family moved to Urbino. Ellie's physical condition grew worse, she became confined to a chair as the fits became more severe, but she was taken everywhere we went – to visit a bar for tea and cakes, to go for a trip out to visit a castle or museum or to a Christmas festa with groups who had handicaps of various forms, some sadly cast off by parents who only looked for what they saw as a 'model' child. Ellie had a limited attention span as she was constitutionally hyper-active. She could never 'speak' to others in a conventional way, but a sudden smile from the corner of the mouth or a caressing tug on the arm 'spoke'. It was clear I think to all that Ellie would never have got better in the conventional sense. A limited life then?

Yes, if you looked at the bouncy children playing games with balls in the park, but, the life given and accepted, every possible opportunity was created for Ellie to expand her life to its limits, and enjoy it to the full and never – ever – to think of herself as handicapped. And, I believe, she never did.

## FROM MARK (BOB)

Reflecting  
on the Living Memory  
of the Little Imp.

Eleanor. The Little Imp

She was "Bob, to me," and I was "Bob to her." A bit of a mutual admiration society. In truth I saw her as "The Little Imp."

As life goes by, all of us will have lost friends and relatives. I suspect that it is true, for most of us, that only a few who have passed on assume an enduring presence in our thinking.

For me, the Little Imp lives on and I am sure in a similar way she has touched the lives of many.

Though manifesting a complex array of problems, Eleanor was also very straightforward. What you saw was what you got. She was feisty and full of raw emotion. There was a strong sense of justice and therefore injustice, usually vocalised in an uncompromising way. Sometimes blazing.

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Frequently expressing raw angst. Often very humorous. Typically Eleanor demanded attention, and let us all know if it was insufficient. She had a devilish sense of humour. Impish. Loving to push the boundaries. She loved testing people's reactions, or rather over-reactions. She knew how to work the crowd and could be quite insistent, until she engineered the capitulation of adults, who realised it might be prudent to beat a hasty retreat. She was, in her own way, a consummate politician – singular in pursuit of a goal, and fully aware that others might perceive the folly of opposition. Perhaps some of the following anecdotes illustrate these things? Eleanor loved to shock. On one occasion, I observed her, as a young child, in the front living room of the house in York peering into the street, through a gap in the lace curtains.

Two elderly ladies were slowly passing by outside, in front of the window, along the pavement. Eleanor tapped loudly on the inside of the glass and both ladies instantly turned to look. All they saw were Eleanor's two fingers, as she kept the rest of her body hidden. Her timing was perfect!!

Another memorable episode I witnessed, personifies Eleanor's wit and ingenuity, in a way which demonstrated her irreverence for convention, as well as a real zest for outlandish "boundary pushing." Eleanor loved to see what reaction she might be able to provoke!

As a young child, I came across her once outside Dagmar's house, with one hand fully disappeared inside the arse of a sheep. The expression on her face was a picture of triumphal glee. And she was delighting in the stunned expression on mine!!

On another occasion, Eleanor asked Bernard why Martin had received new shoes for Christmas. When told that he needed new shoes, she insisted that she did too! Bernard replied candidly, that she didn't, because her shoes were perfectly ok. Thinking laterally, Eleanor deftly undid one shoe and threw it on the roaring fire, so making the point that she had joined Martin, as one of the shoe-needy! Eleanor loved music and one might say that she had a "broad" taste. Whether it was the loudness of one of Martin's classical piano renditions, or the more lyrical "Grand Old Duke of York," sung by Bernard, her face often transformed into rapture. Loudness appealed. She loved shouting, often repeating single words or phrases – almost as a mantra.

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(Eleanor and Mark)

In this way Eleanor knew how she could cause enjoyment and evoke humour in others. Indeed, one of Eleanor's favourite words was "CRASH!" When she was sharing aloud with the world, about "CRASHING," Eleanor would burst into spontaneous peals of laughter, and this humour was one of many of her endearing qualities.

It is particularly nice to remember the way Eleanor related to those close to her, as carers. Superficially, she may have seemed to have been indifferent to the efforts made on her behalf. But she bonded in her own special reciprocal way with Giuliana, Bernard, and Martin, Nunzia, Oriella, and the many other helpers who became such a permanent part of her support mechanism, and who became her "special others." That Eleanor had a very special regard for Michele, shone through. In them, she trusted.

By supporting her and transacting on a daily basis, those close to Eleanor became fellow

travellers. And, if I am right, the one thing above all else that they shared in common, was the way that Eleanor touched their souls.

In the later period of her life, Eleanor was much more physically challenged. And this was distressing to watch. I personally felt inadequate, in comparison to others, who communicated more successfully with her.

Of course, witnessing this physical decline was only a partial difficulty for the sensitive onlooker, in comparison to Eleanor's own daily endurances.

And what do I really know about her "daily endurances?" Perhaps not a lot. Simply a witness's view. In reality it seemed that Eleanor had no choices, but to struggle on. This was her daily reality. Often she was unable to surface above low mood, which sometimes became abject misery. She was unable

to articulate a comprehension of her own plight, though often seemed to feel sorry for herself. In this sense, her daily experience had a real element of "struggle" to it. At the time of writing, I have not seen my own daughter for 15 years and this has been my own daily challenge, seemingly without an end in sight, and sometimes pitching me too into despair. Given this context, why was



(At the airport)

Eleanor's journey so important to me? I think it was because she exemplified the fact that against that daily struggle, she had no choice but to carry on. Qualities of stubbornness and determination, often shown as simple bloody mindedness, surfaced into a self preservation. And this I witnessed. And, in a way, I therefore believe that Eleanor gave me strength too. To struggle against less adversity. To reflect and try to put my own life issues into perspective.

Visiting your family frequently, as I do, has meant that the "Parodi Worthington" experience has been the closest I have had, over 20 years, to sharing in a family life, not available elsewhere for me. And Eleanor has been part of the woven thread of that tapestry. Without words, Eleanor was very communicative. Sometimes "Resigned." Sometimes "Fed up." Sometimes "Stoical." Sometimes "Angry." Always "Aware."

But very often joyous too. For me, Eleanor's fortitude shone through it all. Without speech, her eyes spoke volumes.

Her funeral Mass was testimony to the love she evoked in others and the sense of a journey we all partly shared. A large gathering of friends of all ages. The partially abled particularly missing one of their own.

Eleanor was a *raison d'être* of her family's life. Many battles were waged and won by them in the name of equality and inclusion, enhancing Eleanor's quality and length of life.

But those others whose paths crossed Eleanor's path, gained lots too. And I count myself as privileged, among them.

P.S.: Responding to the invitation to write about Eleanor has been difficult. I have attempted to achieve simple recollection and observation, rather than eulogy. But I cannot write about your daughter, without thinking about my own daughter, and what she means to me too. And I suspect this is true of other contributors also. Emily enjoyed many delightful shared experiences with Eleanor, during our frequent visits to the Parodi Worthington household. And I hope she enjoys reading this collection of recollections of an early childhood friend.



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JULIE  
JEREMY  
JUSTIN  
EMMA  
HELEN  
JOANNA  
TO ELEANOR

I met Eleanor whilst she was still a bump, before my own family was completed and before any of us knew who she was, or what she would bring to our lives. Now, she is a rich source of reminiscences, of laughter and at times remembered surprises which now, with the passage of years, also form part of that warmth of memories. Deeply missed by many, she is always available in our thoughts and continuing conversations. When, just before Christmas 2009, I presented my family with the request that we come up with something to write about Eleanor the stories were immediate.

“You’ll have to mention singing happy birthday in that church in Venice” – imagine the silence as Mass begins and a three year old seeing the candles and singing at the top of her voice and imagine the stifled giggles of those who knew better!

“And the Yankee doodle song”

“Her beautiful art work”

“And her fantastic ability to speak in English or Italian just at the right moment- swearing in English at her Italian teachers and in Italian at the English ones” (how enviable my children found that one)

“That Easter egg hunt we did in Italy and all playing dressing up with Eleanor and Joey as little fairies”

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“And oh yes, the Chinese women, the one in the fish and chip shop whose chips she pinched, and the one in the park who she kicked.”

I contributed my memory of Eleanor’s meticulous scrutiny of the various samples of dog shit to be found on the pavements of Genoa on our memorable visit to the flat there - and the remembered disdain of Justin and Martin that this should be of interest to anyone – as if! Joey remembered being ‘tied up by Eleanor while she tried to set fire to me’ and the family virtually chanted “Mustn’t push Joanna down the stairs” and laughed at the inevitable outcome when Eleanor nearing the top of the Thorpe Street stairs couldn’t resist pushing Joey who was following her.

They explored together, made potions together, had whooping cough together, used prodigious amounts of imagination and energy and loved each other.

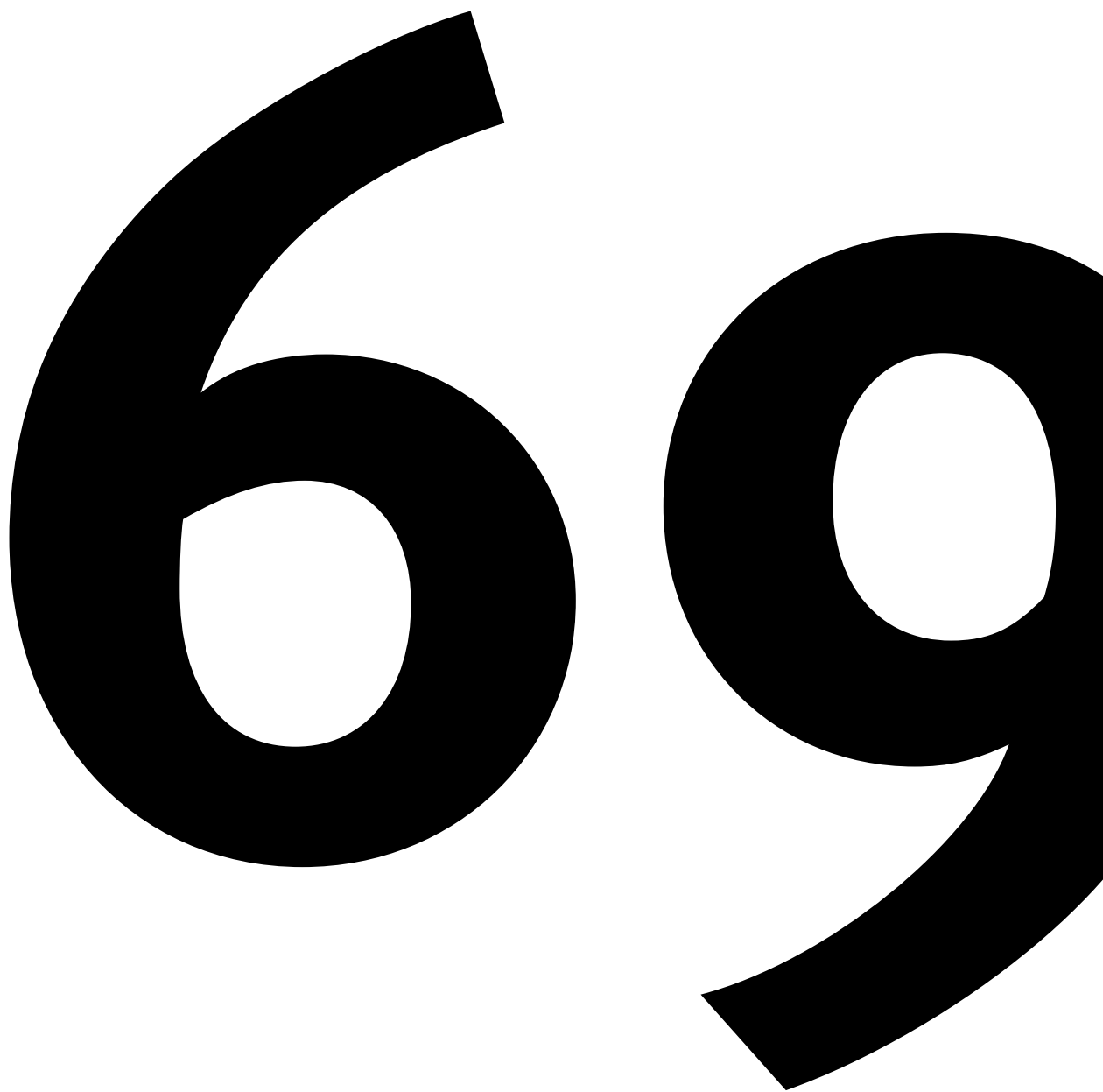
Helen held dear a memory of Eleanor smashing plates in York after enjoying a game in Italy that hadn’t involved the real variety – that, and Eleanor’s ability to carry apple juice across the room to someone and then ceremoniously pour it into their lap was her particular memory.

This still makes her chuckle.

Eleanor was special and brought a special dimension to our lives. She dared do the things they would have loved to do. She ‘got away with it’. They were fascinated by the way adults coped with her and also wary of the kick to the shins that her boots could deliver.

The memories take them back to their childhood and to the yearly visits to Thorpe Street – always anticipated with delight and always talked about between times.

One of my final memories of Ellie was when she was so poorly but still managed that same smile when Giuliana and I talked to her of playing at being little fairies with Joey



DAILY LIFE  
in Urbino

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# VIV MICHELE CHARLOTTE

**It has been quite an undertaking to write about ‘our Ellie’, not a simple task at all. But of course that was to be expected, because ‘our Ellie’ was not a simple person, and one of the things in which she excelled was arousing very complicated emotions in people. It would be wonderful to write about one ‘simple’ emotion such as love, but we all know that love has many facets, and if one ever thought that love was simple, then that thought would have been completely overturned after spending time with Eleanor! Anyone who spent a lot of time with her, soon learnt of the many facets**

**of love, and we all did learn so much... we learnt of unconditional, totally devoted, dedicated and unselfish love, that her immediate family cocooned her with, and that was one of the greatest lessons of all of which volumes could be written, but here I would like to recall some of the other emotions and facets of love that ‘our Ellie’ induced. I cannot possibly write in any kind of chronological order, because so many memories and stories come flooding in, and I feel it would be wrong to put them all in order, so here we go. Eleanor was a very very social being, she loved nothing better than to be going somewhere, arriving somewhere, or finding herself in a crowd of people. She loved the company of young people, and if they were a couple of years older, all the better, because she used to study their ways of dressing and monitor carefully their language just waiting for a swear word, or an ugly phrase, and she would squeal with delight and indignation, and then correct the poor youth explaining in no**



(Viv, Charlotte and Eleanor)

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uncertain terms that he should not say such things! Eleanor was guest of honour at a 26th birthday party which I held for one of my students. In all I think there were eight or nine 26 year olds all laughing and singing and wanting to eat a rather large and sticky birthday cake. Eleanor insisted at all costs that she sat down next to one young man, who was quite a comic. She was transfixed by him, he was rather handsome which was not lost on Ellie, but she insisted and insisted again that he was just like her, 'the same', 'he's the same' she repeated so many times. She was very urgent about all this, and I confess that I really didn't understand what she meant by this sameness. The young man started to tell a story to everyone in the room in a very theatrical manner, changing his voice and assuming different characters and making everyone laugh, then he started to stammer dreadfully and his eyes rolled back, and as all his friends laughed, I realised that this was not a joke, he had started to have an epileptic fit. Soon the friends started to panic, but I just knew what to do, thanks to Ellie.

An ambulance was called, the tegretol found, and Ellie sat there transfixed just repeating 'poorly, poorly, like me, like me, the same'. After the young man had been taken to hospital, I sat holding Ellie's hand, and realised that somehow she knew that the young man suffered the same as her. Although she didn't have all the words to make me fully understand she made me aware of a deeper silent understanding.

Not being a stranger to illness and pain, our Ellie was a bit of 'fix it' for people not feeling too well. My partner, and much loved friend of Eleanor, was grimacing as he ate at the table one day, Ellie asked what the matter was and when he explained that he had a toothache, Ellie disappeared for a while and returned to the table with a toothbrush and a towel, quite sure that the problem would be solved after a good brushing!

On another occasion, I had my leg in plaster, and Eleanor pulled up a footstool, took hold of the plastered leg, put it on the footstool, and announced all would be 'better' now! When she saw someone in pain, or poorly, she was the first to help as much as she could.

As she became a young lady, she gave fierce vent to her all time passion for shoes. My daughter Charlotte the same age as Eleanor, or as Eleanor would have it, two months younger than her not hiding the superiority of her age, shared the same passion. There was a dreadful

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rivalry between the two regarding shoes, a rivalry which lasted nineteen years, gym shoes, school shoes, slippers, wellingtons, red shoes, pink shoes, new shoes for Christmas, new sandals for summer, glittery shoes, high heeled shoes, and the first thing Ellie would look for when Charlotte was around was the footwear! When Charlotte gave Ellie her stilettos, wheelchair or not, they fitted! Ellie was also a stereotypical fast food gourmet; she loved all the things which are bad for us, Coca Cola, chocolate, chips, cheese, pesto and cake! Meal times when she was younger were an adventure, her logic was to eat the cake, the chips and the cheese first and leave the boring vegetables and salads and fish until last! In this respect she was very strong and determined to have her own way, and knew how to manipulate people into letting her have her own way. So, when Michele and I were in charge of meals for a week, looking after Ellie while her parents were away, a cunning plan was adopted of us sitting down and organising the menu, who would outwit



(Eleanor and Michele)

who? Spare ribs, yes! Meatballs, yes (if followed by Mortadella), Fish fingers yes, with a little pesto! Spaghetti and ragout yes, followed by some biscuits WITHOUT chocolate. The week passed serenely, but when the spare ribs were served, there was the tenderest request to cut them up as small as possible because she couldn't bite them properly. A small glass of Coca Cola was the prize at the end of the week (made even more heavenly because we promised not to tell mum!) When dietary restrictions were necessarily imposed, Michele observed her diet, no cheese, no milk, no cake, no yoghurt, because that was how strong people ate! She so wanted to be strong, it was important to her, and through the years both Michele and Ellie became the 'strong pair.' Then Eleanor fell out with me... she so adored Michele, that I was deemed the unnecessary part of the partnership! She was jealous of me, and I was dismissed in no uncertain terms during this time. Fortunately for me her attentions later turned to another young man, and I was in favour again.

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There are so many stories and so many memories, but we all learnt patience from her, we watched the frustrations of not being able to communicate clearly all the time, we saw and learnt bravery from the many epileptic fits that she endured. We saw the joy of being with a crowd, despite limited mobility. We saw the love for her special friends and her animals. We were disarmed on her insistence to do and to eat the forbidden! She made us understand her emotions, and revealed at times an almost psychic understanding of some situations that she didn't have the words to express, she showed her anger physically and vociferously, she cared tenderly and with great attention, and her sense of competition and rivalry was ever present. She could also be naughty and challenging, but those stories remain between us!

When Ellie left us, I had a dream, and it is a dream that I know had great meaning and it had a clear message. Eleanor was sitting on a chair with her feet up on a footstool. She was well and beautiful, she had her hair blonded in a well cut bob, she had a fuchsia pink satin skimpy top which accentuated her big incredibly blue eyes, she had a flared skirt and her long colt like legs were crossed, all attention being directed to her 'killer heels'. She had the most wonderful smile, and she was holding up a flute of sparkling wine in a cheeky, party like salute. I am so sure that is how Eleanor is now, and even more sure, that that is how she imagined herself to be as a young woman.

It was a pleasure to know you, and we all learnt from you. We still love you and miss you and I pray that all the gods are looking after you.

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## LETTER FROM ELISABETTA AND MAURIZIO

Dear Eleanor,  
Maurizio and I met you in 1992 when you were still a child. We lived many months with you and your wonderful family and we shared some beautiful moments. Then in 1995 we got our Degrees, in 1996 we got married, then our first two children arrived....

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In the winter of 1998 and in the summer of 1999 we came back with our two small children to visit you, then our paths separated for a while.

However, your mum and Martin wrote to us to let us have your news. At a certain point, we learnt that your health had deteriorated which for us was very painful to hear.

Some years ago, after various phone calls we came to your house to see you and we passed a lovely afternoon together with our three children (who in the meantime had grown up considerably), they played puppets with you or they read you books. When it was time to go home, I remember you cried and it really was an emotional moment because we realised how much we meant to you and how much you enjoyed our visit.

P.S.: Maurizio wants to add that in that long period in which we lived together, he has many vivid memories of you, and in particular when you both repaired the moped and you criticised him, and as for the walks you took together, there is enough material to write entire chapters!

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## REMINISCENCE BY ANGELA



(Eleanor's portrait by Angela)

“I met you in my dreams, unaccepted Eleanor,  
I wanted you different  
One day there was that meeting  
You were as you were, without a why  
And it was good”

Thinking about it again, I don't believe that Eli was a fragile creature, any more than anyone else.  
I believe she was as she was, that's all.  
And that was a good thing. But this knowledge isn't taken for granted because it comes from lucidity free from social convention which flows from distinct conditions, such as love which unites and doesn't just separate.

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# MARGUERITE'S RECALL

When I think of Eleanor I recall a warm, loving home; a picnic in a meadow; visits to markets; pageants and an archaeological dig.

I remember her enjoyment of what we call in England, “girly” things: pink, sparkly T shirts, pretty shoes and purses and bags.

Eleanor spent some time with a young, local woman who was planning her wedding. They would watch videos about dresses and all the paraphernalia of weddings, which seemed to fascinate Eleanor and tickled Giuliana. I feel that Eleanor’s life was enriched by the huge efforts that Giuliana, Bernard and Martin made in harnessing all their talents and skills to provide wonderful care and experiences for Eleanor.

Brief were my days among you,  
and briefer still the words I have spoken.  
But should my voice fade in your ears and my love  
vanish in your memory,  
Then I will come again.

Kahlil Gibran, The Prophet



(Marguerite at Eleanor's house)

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# OCTOBER '98 – DECEMBER '99.

## LINDA

Eleanor,  
I miss you  
and you are always  
in my thoughts.

For many years I had worked with young people with brain damage of varying degrees, so when I took over the position as personal carer to Eleanor (or as Ellie as I knew her), I thought it would be very easy. Not so, when we first met, I was so happy to meet her, Ellie just glared at me, no hint of pleasure or excitement, I was just a carer and she was not going to be patronised or fobbed off with platitudes, pleasantries and smiles. It was the beginning of a relationship that would test, frustrate, baffle, surprise, delight and finally create in me genuine love, respect and admiration for Eleanor.

Eleanor was strong, strong in her likes and dislikes and very strong willed. It was that strong will that made the biggest impression on me. Many times I saw how weak in her body she was with the seizures, and yet, when I took her to school, she would summon up all her physical strength and, with determination, walk into the school. I do believe many people in her position would just curl up and simply not bother. Her will was so much stronger than mine. I remember once, when I felt she should apologise to me, she refused. I told her firmly that I was not going to drive the car home until she had – we sat in that car for nearly 2 hours, I finally gave in. However, Ellie knew she was wrong and said 'sorry' on her terms and when she was ready.

We had our ups and downs, and I used to think she was testing me, to see how much commitment and love I really had for her. One week, she refused to speak to me in the mornings and she would look at me with what appeared to be contempt. I tried so hard that week to be normal, chatting and smiling with her,

I got nowhere. Finally on the fifth day, I gave up trying, I carried on with chatting, but inside I felt hurt. Eleanor immediately sensed this, apologized, hugged me and we were back to normal again. She was very intuitive to my feelings and that quality meant a lot to me.

Eleanor, with her mum or dad would often meet me at Rimini Airport, and I always looked forward to seeing her again. Spontaneously, she would run into my outstretched arms and we would hug each other. (What a difference from our first encounter).

Our emotions and feelings were genuine, we were pleased to see each other again.

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# A LETTER FROM CLAIRE

Dear Ellie,

How do I remember you?

Everyone who met you was immediately drawn to you.

You had a pure little soul and a simplistic attitude to life. You did not know hate, only the lack of coca-cola would make you cross.

People in your own age group were fascinated by your sense of fun and your loving and sharing nature.

One big thing to remember about you was your care and compassion for animals– big and small.

You could also put us in embarrassing, in funny situations in the shake of a lamb's tail. I know you can remember these times Ellie. I used to watch your face then as you plotted the fun and stand back to see the reaction. Oh! How funny these times were!!

Can you remember how energetic you were – always on the go – what's next?

How you loved people. Anyone would do. Fat – thin, Tall – short, Girl – boy, Any race/ colour/ religion. All this was irrelevant in your world.

You liked nothing more than a party or big gathering with plenty of food for everyone. That was your idea of bliss!

Can you remember the times we used to sit on the bed trying out make-up? You could be such a girlie as well as a tom boy.

Some days we would go for a drive in the car and we would study the beautiful countryside and sing songs as we went along. Can you still remember the “galloping major”?

Then I can recall your interest in cars. I can't remember your favourite, but maybe it changed when you saw a better one. Sometimes you chose them for the colour, sometimes for the model. In fact you could identify many different makes and models.

Do you remember the special Halloween when we all made lanterns from jam jars and candles? It was a cold and foggy night and we all walked along the lane dressed in Halloween costumes. We were looking out for witches. That was fun wasn't it?

There was another time when we went out for a drive. We were passing a nearby town and we heard a band. It turned out to be a festival and they were throwing sweets everywhere for the children to collect. Everyone was dancing and having great fun. Can you remember this time, Ellie?

Your face was a picture! Like pennies from heaven!

Ellie... This is how I remember you and how I always will. You were such a major part of my life and you taught me a lot.

You are a little angel now but you can be proud of the life you lived.

I am proud to have known you.

Love x

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SHARED INTERESTS

# MY SISTER/ MARTIN



(Eleanor and Martin)

It is not easy to write about my sister Eleanor. Just as it was not easy to talk about her while she was alive.

“Oh, you have a sister? And what does she do?”. A question I found difficult to answer. Because Eli’s paradox did not lend itself to ready summaries. On the one hand, illness, suffering, tragedy; on the other, strength, vitality, happiness. These two aspects admired in Eli as in no one else I have ever met. To explain one without the other seemed not to do her justice, and to explain both together was impossible. This difficulty persists even now. To know who Eli was, what her system of values was like, how to understand her reactions to people and events, one needed to be acquainted with her, and see her in action. I think that even we, her family members, never fully understood her world. What to say to an outsider?

Despite her brain damage, Eli was far from stupid. Indeed, she often displayed great intelligence, albeit not in the conventional meanings of the word. But this did not

prevent her, as it prevents many others, from being a simple person. (Not a simpleton, a simple person). Concrete, fulfillable desires (tegolini-cakes, coca cola, pets, school satchels); concrete affections (kisses, tender gazes); un-selfconscious rage and grudges (scratches, punches, bites, slaps); an elephantine memory; constant interest in the world of commercial goods; the constant desire to make a racket; inexhaustible energy. Less simple than herself was the life that, in consequence of her medical misfortunes, she had to live. At least until 2003, when she ended up in a wheelchair. I do not remember much about the years before that, and to revisit them fills me with impotent sadness. The summer in which mum asked me not to tell people how she came to have scratches on her face. The twenty-four or more consecutive months in which Eli hardly said a word. The period in which her epilepsy was less

Eli's trajectory through life was not,  
then, the downward bend  
of inexorable decline  
which it might have seemed.

controlled, and Eli fell down as if dead up to thirty times a day; we could not always catch her, and she suffered broken bones and teeth. The time we were chased out of a bigoted and oafish village. There were also happy moments, of course, but, at least in my recollections, they occurred in the shadow of recent and future worries. Spring 2003 brought about an enormous change. For months Eli had been getting physically weaker, to the point of not being able to stand up unassisted. In March she ended up in intensive care, then in the lung ward, then back in intensive care. It was terrible. She was given a few weeks to live, and sent home to pass away among her loved ones. But this was not yet to happen. After a few weeks her condition stabilised: unable to move except for her facial muscles, or to talk, Eli began a new life in a wheelchair.

One of the biggest paradoxes is that this period, the abilities and independence she had lost would seem to make the most tragic, was in fact a very happy one for Eli; apart from her earliest childhood, the happiest of all. Immobility and aphasia removed the speech-related and behavioural barriers which had previously made her the object of suspicion, fear or disdain. It brought out her beauty, and Eli became a sort of little angel that moved one to tenderness. In the words of a visitor, 'a little Buddha'.

Still in 2003, there began a series of close friendships between Eli and her helpers. These were extremely important to her, and moving for anyone who observed them. Listening to her helpers chatting, or hearing the many things they told her as a confidant, Eli came to take part in the lives of several people she loved, more or less of her own age. She was able to develop ties of information and affection which had previously been denied her, but now helped her to grow as a person, making her more carefree and more generous.

One reads this last sentence in a matter of eight seconds, but it contains one of life's miracles, and, wording aside, it should be written in marble for posterity.

Eli's trajectory through life was not, then, the downward bend of inexorable decline which it might have seemed. And it would be unfair to remember her only as a person afflicted by deep troubles. She won some enormous moral victories, on a scale beyond the capabilities of many of us who remember her, and, in addition to empathy and sadness, Eli most of all deserves our admiration.

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# A WONDERFUL MOMENT IN MONIA'S MEMORY



My baby girl looks at me with her big blue eyes, and I remember the moment in which Eleanor and I flicked through the pages of a book with babies' faces, we arrived at a picture of a beautiful little girl with big blue eyes and we said to Giuliana 'We would like Anastasia to be like this, this would be ideal!' Immediately we all started to laugh. This is just one of many wonderful moments that I lived with Eli, but I often spoke with her about the time when I would become a mother, this is the memory that I want to share with you all!

(Eleanor and Monia)

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# FLAVIA'S THANKSGIVING

Thank you Eleanor  
I learned from you.  
Fragile Angel, eternal child.  
You taught me how to love.  
A simple, sincere unconditional love. Love for simple things.  
I loved losing myself in your expressive eyes which knew how  
to embrace the entire world.  
I loved your expressions, childlike and mature at the same time.  
I loved the way you inclined your head when you questioned.  
I loved to watch your silent lips when they broke into a smile.

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Laughter and tears were your words, which appeared like butterflies and with their wings caressed the hearts of those who knew how to welcome them.

Thank you to Giuliana, Bernard, Martin and Nunzia who taught me how to listen to you.

I have often asked myself how Eleanor felt when she left us. I know that she wasn't alone. She had with her the people who were the dearest to her. It shouldn't have been so difficult to say goodbye to them: in that moment she was loved, as she had always been loved. A love so beautiful that when it was her time to leave us, it let her go, with great courage.

They accompanied her leaving with music so that her final journey was peaceful and joyous. They let her free, like a bird. Probably they didn't notice the moment in which her soul flew away. She was freed like a butterfly from her body, finally free to flutter around as she liked. Every now and again she comes back to us and she touches our thoughts with her wings.

She hasn't forgotten our love.

## LETTER FROM AGNESE

Dear Eli!

I am writing to you because I am sure that you will read this.

Our story began many years ago when we were two children playing together at primary school. Then many parties, dances, and San Giovanni. You were always present at all this and every single time you gave me a smile of welcome.

One fine day we met again, face to face, and we spent two days a week still together, telling each other stories, drawing and walking among the green leaves.

From here I began to reflect. I went home tired but what had I done? We had simply sat on our chairs like two queens drinking and eating apples.

It was something moving in the depth of my soul and with every day which went by my joy grew. Do you think it is possible to be tired and full of energy at the same time? This is the effect which our summer afternoons had on me. I learnt again to be stupefied by nature, by its colours, I learnt patience.

I learnt that there is not a time to do things but that we are time. And so when we are no longer our time here is at an end.

You taught me to appreciate a small smile, a tear. There were many times, you know, when I would have liked to enter into your gaze and understand what you were thinking, but then



you would tell me.

Thanks to you I went to Ireland to work with differently able children, and I succeeded even with my unconscionable English.

How many wrong pronunciations would you have heard from me?... but you, always sweet, never told me off.

I am sorry if I lacked respect for you. I thank you for always being here... now you see many things and perhaps if I prick up my ears you are whispering them to me.

When you passed away I had only one means of salute: music. I know you didn't always like the piano, but I thought you would like Bach. Now every time I play those notes you are in my eyes. I have always thought that the angels hid themselves in strange clothing but you went out in the open and I will not do without your teachings. Thank you for all your patience and for the love of life which you gave me. To your family, too, I owe thanks.

To Giuliana for her force of will and for the optimism which emanates from her. To Bernard for his silences and his great heart and to Martin for the notes which he played you and for being the brother that he was.

To you, sweet maid, a great thanks for being an example to me every day.

A playmate, Agnese.

## LYRIC FROM RICCARDO

I remember very clearly some of Eleanor's very lively characteristics,  
 I always saw her as a rare species of subversive punk.  
 She liked to overturn the world's rules.  
 A true free revolutionary  
 With a profound sense of belonging.  
 She wasn't from one place or another,  
 She belonged only to herself,  
 That which could be mistaken for selfishness  
 Was a profound awareness  
 Of a living being.  
 A fiery gaze which burnt everything  
 Illuminating the plain and making it clear from a distance what it means,  
 You could distinguish from a distance if something was her work.  
 I remember very well her profound physicality,  
 The infinite need for contact  
 Between her and the world, after  
 The world had to be pushed aside  
 To allow her to react  
 And with a finger ignite everything.



(Eleanor)

She didn't approve of tears or sadness from our part  
 Neither did she let us weaken by events.  
 I remember at the slightest hint of sadness,  
 Her face would light up with an air of questioning  
 And she asked: 'Why?'  
 In that moment her expression was sweet,  
 Because she didn't have the concept of "finish"  
 As in conclude.  
 For her everything was excessive  
 Everything was lived to the full,  
 There was no time to give in to discomfort.  
 I think even facing death,  
 She would have given a hearty laugh and she would have asked:  
 "Why are you so sad?"  
 And hopefully, then she would have smiled.

I think this,  
 Nobody can contradict,  
 Because certainly she was not a ceremonious type  
 And even less compliant.  
 For her we were all totally equal  
 And no-one could resist in the face of her irresistible provocations.

She truly is one of the freest people that I have ever met,  
 With limits,  
 Unstoppable,  
 Embarrassing  
 And being so unique, full of positive force  
 Which renders her one of the positive energies of the universe.

## THE FORCE OF A LAUGH, ELEANOR AND VALERIO

The purity of others' teachings is for us an impurity.  
 Do not distinguish anything in reality as pure or impure.  
 The wind follows the wind. The image represents something  
 which sweeps away every cloud from the horizon.  
 The represented heaven is, in particular, the mind: the mind which labels,  
 analyses, judges, criticises, distinguishes and separates.  
 The representation invites one to look at existence, what  
 happens to you, everything, directly, as simply facts, naked and  
 raw, without labelling, without saying right or wrong, good or

bad, that is, leaving aside the mind and its constant judgement. Enter into contact with the reality of things, do not project onto them any concept or presupposition; avoid colouring reality, live as a clear sky!

In this way you will grow beyond every purity and every impurity. And remember: it really is the idea of purity which creates impurity, that is inevitable! In this lies the principle of conflict, of dichotomy, of the separation of life, which, however, remains, in its essence an undivided and indivisible unity.

It will not be easy: every one of our thoughts divides, analyses and discriminates.

It is a long standing habit which dramatically conditions our perception.

Thought, in itself, is a condemnation

You say that something is beautiful, but in that way you will have condemned something else as ugly.

And this dualistic attitude, at the same time, divides you internally. Inside yourself you are two people! One part of you is good, the other is bad; and obviously you identify with the good part, at this point you will live a continuing conflict: you will never be able to be an individual, you will always be something divided and struggling with itself. In that way you will not know peace or silence. You will feel only tension and anguish. And that is the way you will feel without knowing the reason.

How will you be able to be at peace? Where will you put your bad side? You will have to destroy it and we are talking about you: you cannot destroy that part. You are not two realities.

Reality is one. Only because of your aptness for dividing have you dissected external reality and in consequence your internal reality.

You can win only if you do not divide.

How can one be undivided? Do not condemn, do not call one thing good and another bad. In every concept merely distinguish purity and impurity. Observe the world, but say nothing. Be ignorant, do not be too wise. Do not label, remain silent, do not condemn, do not justify. Little by little that silence will enter within you and if on the outside there no longer exists any division it will disappear too from your inner awareness, for the two things co-exist. At that point all will be immersed in a single reality, You will become an organic unity: there will exist nothing pure or impure. You will know the real.

This technique serves to create a unity within you, to have an undivided existence, free from every conflict.

I have chosen this passage because it represents, effectively, the idea I have developed of the emotional and spiritual life of Eleanor. She is the only person in the world whom I have seen follow this path. A bitter path, hard and full of difficulty; nobody has been able to change this destiny, but she,

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in her relations with others, succeeded in giving an unexpected content, wonderful; a touching adventure which has been a gift to all of us...

I gladly recall those eyes which sparkled with joy every time I met her, my useless words proved superfluous and of little importance, she used a personal language, she spoke with her inner strength, she entered inside me to the point that I felt her vibrate and I silently awaited that analysis, embarrassing at times, which like an ultrasound scan immediately made me understand what was going well and what in myself I should look at again. This emotion was wonderfully true and every time I was afraid to experience it but had a great desire to feel it again.

Often among the stories told by my mother who lived with Eleanor every day I happen to think and reflect on the earthly situation, where did all this suffering take her? Where did she find the strength to make all what was happening to her? When I suffer she comes to mind, and my problems, my sufferings and my misfortunes are cut down to size, and find a more appropriate place.

One evening about five years ago I was at home with a bad influenza, I was in bed, motionless and in pain, with a temperature which rose hour after hour, and my thoughts went to Eleanor, I wondered how she could be feeling given that she was subject to forced immobility. I identified so much with this great suffering that I tried, a little naively, to take it on myself, that is, to lighten hers and give her an untroubled rest. It was a hellish night, and a hellish day followed, which came to an end when my mother Nunzia came, and put herself out in a thousand ways to alleviate what I was going through. When I saw Eleanor two days later at her house, I went up to her, I took her hand, as I normally did, caressing her I asked her: "how are you?" She smiled at me with her eyes and, which I was not expecting, I heard a loud laugh.

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## A CONFIDENCE FROM ANTONIO

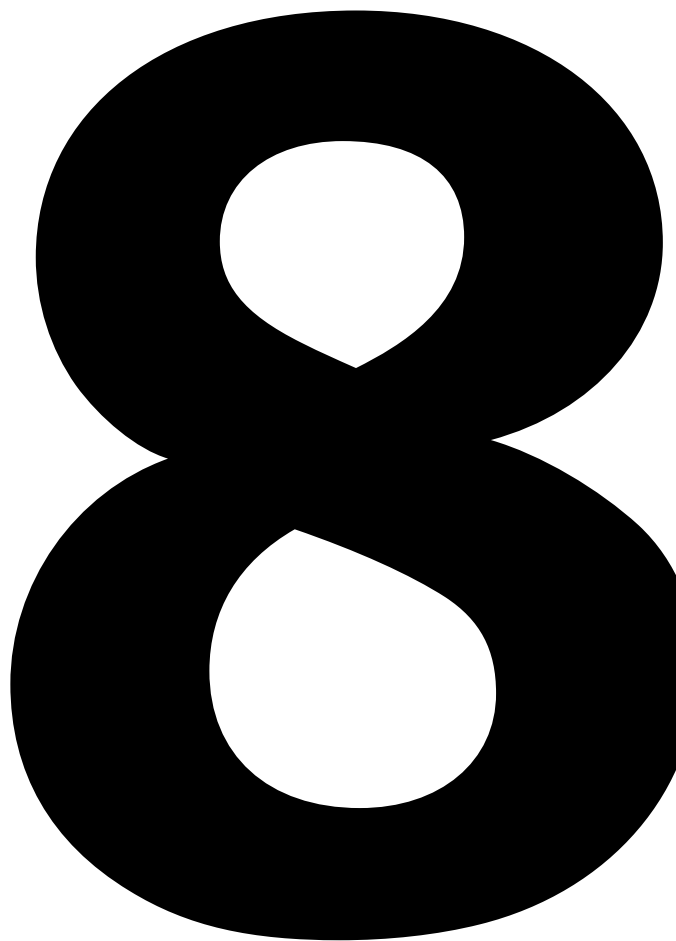
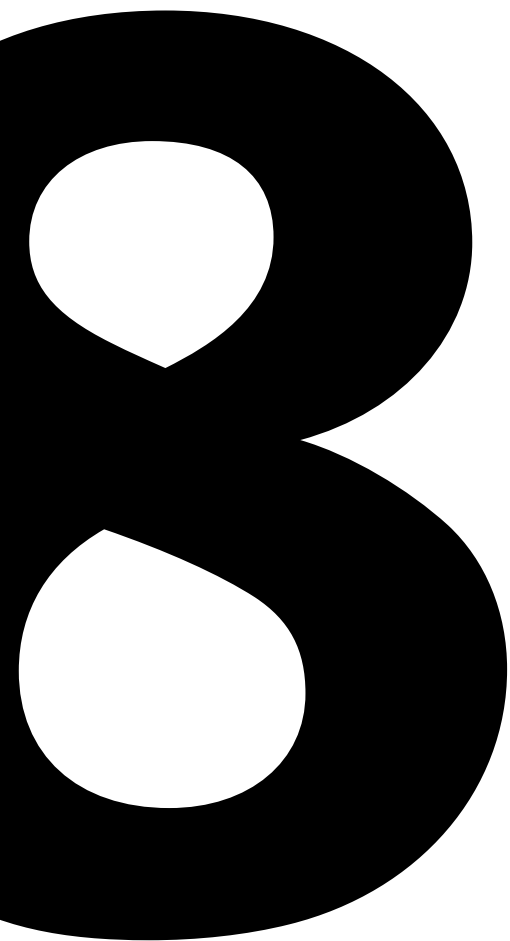
Eleanor.

Since you were a small child I passed time with you  
Can you remember when you were seven years old?  
I was a small and timid explorer and I roamed and roamed,  
we roamed together  
On those hills, we played near the pond with your dog  
and some frogs –

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Can you remember when you were ten years old??  
I can, and I bet your mum can!! Yes, because she had taken  
us for a walk  
On the seafront, wonderful years!!  
Then I saw you again in January 2008, a magic moment  
because three of the four women  
from via Jacopo Ruffini were reunited, women who I learnt  
to appreciate.  
It was a magic moment also because finally I saw you  
and your brother together!  
Magic because Stefanie's children had prepared a show for you!  
Do you remember??? Yes, yes it was really that, where Martin  
played the piano!  
Since that January I haven't stopped thinking about you,  
you are always in my heart,  
With your smile and your strength!!!  
A big kiss, I miss you.

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SUPPORT

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# LETTER TO AN ANGEL

Dear Eleanor,

I remember when I met you in the hospital in Urbino. You had been admitted on the hospital ward for Bronchial pneumonia. A trivial Bronchial pneumonia which however meant you had to be admitted to the Intensive Care ward, where we became friends. Then following episodes of breathing difficulties which were ever more frequent we decided to do tracheotomy to help the breathing, and to speed your return home, which after a time happened. The treatment was started and you were to go home. Eleanor I remember you as a very sensitive girl. You couldn't speak because of the tracheotomy and of your neurological condition, and so you communicated with your facial expressions. With a smile you made us understand that you were fine, with a grimace and a tear, like a grumpy child, you made us understand that something was wrong, and you were always right.

Your blue eyes hid the cruel reality of your actual age. Your smile, always sweet and sometimes cheeky was often moist with the secretions caused by your illness. You found in the Intensive Care Unit your second home with many friends, doctors and nurses to keep you company while you waited for the daily visit from your mum Giuliana and your father. After many days, you finally returned home. Every now and again I would come and visit you to check your breathing levels; your mum Giuliana had become a fine nurse. At home you were happy. You were happy with your geese, your dogs and your cats. I remember well your house in the country where a friendly untidiness blended with culture and peace.

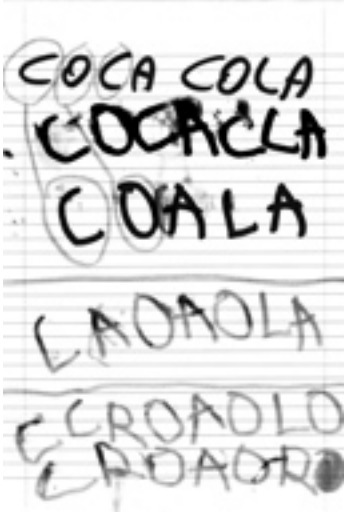
When I came to visit you, I often met a family of deer who grazed undisturbed on your fields where they felt safe. It seemed to me that I had entered the world of fables. Eleanor like Heidi. Essential goods only, no waste, no luxury, everything was simple, everything was love. You were happy and had returned to school, a scene which you appreciated and with your presence enriched the lives of those around you. I remember you Eleanor, with your pale face, moistened lips, your smile that was searching out a caress, with your gaze lost in emptiness, and in silence you said to me 'don't hurt me'. Now I have to go, but I promise you that one day I will come and find you. Ciao Eli, I love you.

Filiberto Martinelli  
Director of Intensive Care/ Urbino Hospital

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# SERGIO & ANNA FOR ELEANOR



(Eleanor's school work)

I remember today, with great sympathy her most evident characteristics.

The continuous struggle to come out of the moments following a crisis and the disorientation due to her illness, the explosions of anger in the face of frustration and consequent difficulties in containing those reactions.

Her interest in new activities, alternating with the strain needed to carry them out and to maintain the ability of doing this over a period of time.

The strong bond she had with her things and the necessity to find comfort in the repetition of activities which she liked.

The difficulty in demonstrating effectively the actual level of her thoughts.

We feel proud to have fought together, she, you and ourselves, with the aim of improving her quality of life.

Sergio Vitali (Child Neuropsychiatrist), Anna Dalmaso (Therapist)

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## FROM PAOLA

Thank you Eleanor,  
you made me feel like a princess.  
A big kiss.  
Thank you.

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My memory of Eleanor, all the times I did the night shift, I saw her and she was calm and she saw me and smiled. She squeezed my hand and had a lovely smile... And now that she isn't here anymore and flies like an angel in a blue heaven, calm and tranquil and will appear always for her many friends and relatives with her lovely face full of joy and smiles...

A LOOK  
THROUGH  
NAJAT'S  
EYES

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# A COMPOSITION BY DANIELA

Once upon a time there was a house in the woods. In orderly disorder, Eleanor everywhere, outside and inside, in musical patterns, in colours, with the cats, and the perfume of her clothes. She was surrounded by sincere sentiments, smiles and never tiring hands, when she was immobilized, she was always a young girl. Whoever visited the house found serenity, a willingness to open her heart, and those blue eyes, small but so large, to see a fantastic world, and to see infinite love. She left her house in the woods, to live her magic, they'll tell you she doesn't live there any more, that perhaps she is amongst the stars. I say that she went away with her noisy geese, but then comes back with me, she always does.

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## FROM INGRID

Dear Eleanor, I remember you with affection. Having an extraordinary sensitivity nothing escaped you and you spoke with your eyes.

You always welcomed me with a smile and you enjoyed yourself, laughing when I joked with you. I told you many things, and I told you about my son Francesco, and you always took his side. You smiled when Francesco, as a young child, moved you in your wheelchair, pretending the wheels were that of a Porsche (your favourite car) and when I asked him if he thought you were beautiful and he answered yes. It's true, you were really beautiful, angelic and the richness of your soul was always evident.

I remember dreaming about you, you were running and I was happy, certainly it was what you always wished for, but you were happy at the same time, immobile, without being able to taste food, without being able to express a word, you loved the world around you, to your mum Giuliana you were 'her Elin' your eyes observed every move your father made, your brother, kindness itself,

always aware of your mood and always ready to make you smile, your Grandma Marie 'her great sweetheart' and Nunzia in whose life you entered.

You loved us all, and we I know loved you.

Through you and with you I learnt to follow your rhythm of a different speed, longer and more intense and I learnt the essence of who you were and the different aspects of your soul.

You do know that for me you were like a sister, and if I was looking after you, you took a lot of care of me managing to imbue me with serenity, calm and patience.

I wish you dear, sweet Eleanor a wonderful journey !!!!! You will always be in Francesco's heart and mine.

Ciao

(Grandma's  
drawing)



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IMAGES OF THE IDEAL

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# A LETTER FROM MARIA TERESA

Hello Eleanor,  
Maria Teresa F is remembering you in her prayers. You Eleanor are my angel above! My cousin and my brother, 11 years old and 18 years old are in heaven. You are not alone, and you won't be the last to be in heaven.  
Many kisses

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## MEMORIES OF ELEANOR BY FAUSTO

Dear Bernard and Giuliana Eleanor's parents and dear Nunzia. In accepting the invitation to write some thoughts about Eleanor to remember Eleanor, I accept your warm invitation and take this opportunity to send my best wishes to you all for a Happy New Year.

I understand what it means to have a handicapped child, because even if you see me doing many things, I tell you that being handicapped myself, and being gravely ill and in need of help, I see just how difficult it is for my mother Lucia and my relatives to sustain me.

Despite everything, your dear friend Fausto walks, and notwithstanding my invalidity I manage to do something, I manage to organize some important events, I am busy with the volunteers and the Archbishops from the Diocese of Urbino, Urbania and Sant'Angelo in Vado His Excellency Monsignor Ugo Donato Bianchi, and the present Archbishop His Excellence Monsignor Francesco Marinelli, they both wanted me to give a testimonial of my illness.

This is my work and my way of meeting people. I have managed to give a voice to the disabled and through this, find the way that can take them on the true path to social acceptance.

Dear Bernard and Giuliana, you are English and in as much as I am just a little thought compared to Eleanor, who was a precious testimony-

I quote from a book of poetry by Charles Christopher Bell, who was made a Baronet by Queen Elizabeth II in England on the 22nd October 1978 for having written and published a book of poems called 'Learn from one who limps and learn how to limp'. That book gave the English a true lesson in life, and the poet, besides having a serious handicap became one of life's teachers

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for your nation, for yourselves and for the whole world.

So, in my way, notwithstanding everything I am trying to learn this path, and who knows if my unsteady walk will bring some good? In our society, as in a family environment sometimes there isn't equality and often to give to handicapped person is difficult for two reasons: Because he is ignored. Because we don't know him.

Imagine Eleanor's surprise as child and see how great the urge to live was, even if forced to live with such suffering which ultimately took her away from us.

Her illness is similar to mine, but in spite of everything I am happy, because even if I have to suffer, I can say that somehow I am fine and be thankful.

First of all I would like to thank my Mum Lucia and my father Giovanni who to get me where I have now got gave his life in an accident the 3rd Dicembre 1992.

The many relatives and local people of Maciolla who always being close made their presence felt in the best and most useful way for my recovery-

The hospitals in Ancona and Fano who are still keeping an eye on me after 44 years, and the hospitals in Pesaro and Urbino who are most important in their help to get me where I am today. The V.A.S.I.S and various voluntary organizations in the Archdiocese of Urbino, Urbania and Sant'Angelo in Vado. The local authority in Urbino who helped me, via voluntary work, to become a coordinator together with other good hearted people. However, I do realize how I am, and I say that I am happy. Things could have been far worse than they are. So, it's alright as it is... even if (things could have been better). Most certainly though they could have been worse. So it's ok as it is. The bottom line is that when you see a smile of suffering, you are also seeing a smile of hope. You are witnesses of this smile. Now you should know how to spread this message being first hand witnesses of love. It would be wonderful and important if this was the action of a disabled person, but to that, especially these days it requires a complete re-valuation by those who hold the reins of society and against the indifference that is still present even in 2010. So it remains that smile which leaves its mark on you, even if it is with us no more, thus becoming an authentic symbol of hope that should touch every individual, helping them to realize that even illness is a genuine message of hope. In the name of VASIS and other voluntary organizations I wish you all a Happy New Year and hope that 2010 although just begun, will be the year of re-evaluation of both healthy and ill people in such a way that illness becomes a ray of hope for a life lived with dignity and respect.

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# MEMORIES OF A SMILE

## BY ERNESTO

Dear Eleanor,  
I saw you suffer and you smiled at me,  
I saw you in pain and you smiled at me.  
In this way you gave me the light of hope  
To return to a tranquil path  
To return to follow behind clouds your smile,  
To understand that silent rain can become a blessing.  
I thank you because you have helped me continue to love this world,  
The joy of giving and the love to share with other less fortunate.  
Continue to smile, just like you used to, together with Marco and Lucia.  
And together with them, you can ask for God's help to aid and protect our dear  
disabled youngsters.  
In your memory we pray that we will all meet again, with hope and faith  
and with certainty that the final  
Prize will be God's glorious light.

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# ALMERINO TERESA LUCIANO

## ORIELLA TO ELEANOR

You passed through our lives like a light which was taken from  
us too soon. The memory of your smile, of your games, of your  
running together with our children remain always in our hearts.  
Now we think of you as a star in heaven illuminating our steps  
and comforting our souls.  
Thank you  
You live on, continue to look on us and protect us...  
Smile and our hearts will be as one with yours!  
A closed door...  
The dark, the cold, then all of a sudden light...  
it's you who still gives us light...

Oh you who are in the immense heavens and in the Light  
of God, protect us, and illuminate our earthly path, pray for us  
until we meet again in Glory and Infinite Peace.

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# ALYNA'S STORY

My story of being close to Eleanor isn't simple, I could write an entire book about my experience to hold in my arms such an enigmatic, rebellious spirit, defenceless, but with an incredible force. My time hasn't arrived yet where I can express myself about things which need a lifetime to reflect upon. They would have little sense or value. A person who truly loves, manages to turn off the 'criticise' button (to be judgemental, to teach, to doubt, to not believe, to be offended etc). I have a disabled son with whom we have a wonderful and productive relationship, I had a thoroughly heartfelt and rich work experience in an Oncology Department, I discovered in Eleanor many subtle levels of existence, which to me had been hitherto invisible. I remember happy and light moments with Eleanor, suddenly illuminated when she showed all her love and feelings with her eyes, her gestures and her sounds (more than words). I also remember moments of total darkness, inexplicable outbursts of aggression, of a lot of pain and my fear and incapability to understand, influence or to help. Even being close in some moments without taking medicines trying to resist. I thought, between these opposing situations, was Eleanor really present? Perhaps in those moments I hadn't turned off the 'criticise' button... Who knows, perhaps God gave me the gift of a precious lesson, not a trial, or an exam, but in his love, a great help to continue moving on, revealing new ways and paths. Who knows if Eleanor gave me the gift of enabling me to refine myself. Who knows if God sent me the Friendly Soul or... was it me...

(Eleanor in Earby)



I found this text, I have translated it to the best of my ability (I am a foreigner who taught herself Italian), and I invite you to read it.

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Once upon no time, there was a little Soul who said to God, "I know who I am."

And God said, "That's wonderful! Who are you?"

And the Little Soul shouted, "I'm the Light!"

God smiled a big smile. "That's right!" God exclaimed.

"You are the Light."

The Little Soul was so happy, for it had figured out what all the souls in the Kingdom were there to figure out.

"Wow," said the Little Soul, "this is really cool!"

But soon, knowing who it was was not enough. The Little Soul felt stirrings inside, and now wanted to be who it was. And so the Little Soul went back to God (which is not a bad idea for all souls who want to be Who They Really Are) and said,

"Hi, God! Now that I know Who I am, is it okay for me to be it?"

And God said, "You mean you want to be Who You Already Are?"

"Well," replied the Little Soul, "it's one thing to know Who I Am, and another thing altogether to actually be it. I want to feel what it's like to be the Light!"

"But you already are the Light," God repeated, smiling again.

"Yes, but I want to see what that feels like!" cried the Little Soul.

"Well," said God with a chuckle, "I suppose I should have known. You always were the adventuresome one." Then God's expression changed. "There's only one thing..."

"What?" asked the Little Soul.

"Well, there is nothing else but the Light. You see, I created nothing but what you are; and so, there is no easy way for you to experience yourself as Who You Are, since there is nothing that you are not."

"Huh?" said the Little Soul, who was now a little confused.

"Think of it this way," said God. "You are like a candle in the Sun. Oh, you're there all right. Along with a million, gazillion other candles who make up the Sun. And the sun would not be the Sun without you. Nay, it would be a sun without one of its candles...and that would not be the Sun at all; for it would not shine as brightly. Yet, how to know yourself as the Light when you are amidst the Light - that is the question."

"Well," the Little Soul perked up, "you're God. Think of something!"

Once more God smiled. "I already have," God said. "Since

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you cannot see yourself as the Light when you are in the Light, we'll surround you with darkness."

"What's darkness?" the Little Soul asked.

God replied, "It is that which you are not."

"Will I be afraid of the dark?" cried the Little Soul.

"Only if you choose to be," God answered. "There is nothing, really, to be afraid of, unless you decide that there is. You see, we are making it all up. We are pretending."

"Oh," said the Little Soul, and felt better already.

Then God explained that, in order to experience anything at all, the exact opposite of it will appear. "It is a great gift," God said, "because without it, you could not know what anything is like. You could not know Warm without Cold, Up without Down, Fast without Slow. You could not know Left without Right, Here without There, Now without Then."

"And so," God concluded, "when you are surrounded with darkness, do not shake your fist and raise your voice and curse the darkness. Rather be a Light unto the darkness, and don't be mad about it. Then you will know Who You Really Are, and all others will know, too. Let your Light shine so that everyone will know how special you are!"

"You mean it's okay to let others see how special I am?" asked the Little Soul.

"Of course!" God chuckled. "It's very okay! But remember, 'special' does not mean 'better.' Everybody is special, each in their own way! Yet many others have forgotten that. They will see that it is okay for them to be special only when you see that it is okay for you to be special."

"Wow," said the Little Soul, dancing and skipping and laughing and jumping with joy. "I can be as special as I want to be!"

"Yes, and you can start right now," said God, who was dancing and skipping and laughing right along with the Little Soul.

"What part of special do you want to be?"

"What part of special?" the Little Soul repeated. "I don't understand."

"Well," God explained, "being the Light is being special, and being special has a lot of parts to it. It is special to be kind. It is special to be gentle. It is special to be creative. It is special to be patient. Can you think of any other ways it is special to be?"

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because without it, you could not know what anything is like  
 You could not know Warm without Cold,  
 Up without Down, Fast without Slow.  
 You could not know Left without Right,  
 Here without There, Now without Then

The Little Soul sat quietly for a moment. "I can think of lots of ways to be special!" the Little Soul then exclaimed. "It is special to be helpful. It is special to be sharing. It is special to be friendly. It is special to be considerate of others!"

"Yes!" God agreed, "and you can be all of those things, or any part of special you wish to be, at any moment. That's what it means to be the Light."

"I know what I want to be, I know what I want to be!" the Little Soul announced with great excitement. "I want to be the part of special called 'forgiving'. Isn't it special to be forgiving?"

"Oh, yes," God assured the Little Soul. "That is very special."

"Okay," said the Little Soul. "That's what I want to be. I want to be forgiving. I want to experience myself as that."

"Good," said God, "but there's one thing you should know."

The Little Soul was becoming a bit impatient now. It always seemed as though there were some complication.

"What is it?" the Little Soul sighed.

"There is no one to forgive."

"No one?" The Little Soul could hardly believe what had been said.

"No one!" God repeated. "Everything I have made is perfect. There is not a single soul in all creation less perfect than you. Look around you."

It was then that the Little Soul realized a large crowd had gathered. Souls had come from far and wide ~ from all over the Kingdom ~ for the word had gone forth that the Little Soul was having this extraordinary conversation with God, and everyone wanted to hear what they were saying. Looking at the countless other souls gathered there, the Little Soul had to agree. None appeared less wonderful, less magnificent, or less perfect than the Little Soul itself. Such was the wonder of the souls gathered around, and so bright was their Light, that the Little Soul could scarcely gaze upon them.

"Who, then, to forgive?" asked God.

"Boy, this is going to be no fun at all!" grumbled the Little Soul. "I wanted to experience myself as One Who Forgives. I wanted to know what that part of special felt like."

And the Little Soul learned what it must feel like to be sad. But just then a Friendly Soul stepped forward from the crowd.

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**"Not to worry, Little Soul," the Friendly Soul said, "I will help you."**

**"You will?" the Little Soul brightened. "But what can you do?"**

**"Why, I can give you someone to forgive!"**

**"You can?"**

**"Certainly!" chirped the Friendly Soul. "I can come into your next lifetime and do something for you to forgive."**

**"But why? Why would you do that?" the Little Soul asked.**

**"You, who are a Being of such utter perfection! You, who vibrate with such a speed that it creates a Light so bright that I can hardly gaze upon you! What could cause you to want to slow down your vibration to such a speed that your bright Light would become dark and dense? What could cause you ~ who are so light that you dance upon the stars and move through the Kingdom with the speed of your thought - to come into my life and make yourself so heavy that you could do this bad thing?"**

**"Simple," the Friendly Soul said. "I would do it because I love you."**

**The Little Soul seemed surprised at the answer.**

**"Don't be so amazed," said the Friendly Soul, "you have done the same thing for me. Don't you remember? Oh, we have danced together, you and I, many times. Through the eons and across all the ages have we danced. Across all time and in many places have we played together. You just don't remember."**

**"We have both been All Of It. We have been the Up and the Down of it, the Left and the Right of it. We have been the Here and the There of it, the Now and the Then of it. We have been the male and the female, the good and the bad; we have both been the victim and the villain of it."**

**"Thus have we come together, you and I, many times before; each bringing to the other the exact and perfect opportunity to Express and to Experience Who We Really Are. And so," the Friendly Soul explained further, "I will come into your next lifetime and be the 'bad one' this time. I will do something really terrible, and then you can experience yourself as the One Who Forgives."**

**"But what will you do?" the Little Soul asked, just a little nervously, "that will be so terrible?"**

**"Oh," replied the Friendly Soul with a twinkle, "we'll think of something."**

**Then the Friendly Soul seemed to turn serious, and said in a quiet voice, "You are right about one thing, you know."**

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We have been the Up and the Down of it,  
 the Left and the Right of it.  
 We have been the Here and the There of it,  
 the Now and the Then of it

"What is that?" the Little Soul wanted to know.  
 "I will have to slow down my vibration and become very heavy to do this not-so-nice thing. I will have to pretend to be something very unlike myself. And so, I have but one favour to ask of you in return."  
 "Oh, anything, anything!" cried the Little Soul, and began to dance and sing, "I get to be forgiving, I get to be forgiving!"  
 Then the Little Soul saw that the Friendly Soul was remaining very quiet.  
 "What is it?" the Little Soul asked. "What can I do for you? You are such an angel to be willing to do this for me!"  
 "Of course this Friendly Soul is an angel!" God interrupted. "Everyone is! Always remember: I have sent you nothing but angels."  
 And so the Little Soul wanted more than ever to grant the Friendly Soul's request. "What can I do for you?" the Little Soul asked again.  
 "In the moment that I strike you and smite you," the Friendly Soul replied, "in the moment that I do the worst to you that you could possible imagine ~ in that very moment..."  
 "Yes?" the Little Soul interrupted, "yes...?" "Remember Who I Really Am."  
 "Oh, I will!" cried the Little Soul, "I promise! I will always remember you as I see you right here, right now!"  
 "Good," said the Friendly Soul, "because, you see, I will have been pretending so hard, I will have forgotten myself. And if you do not remember me as I really am, I may not be able to remember for a very long time. And if I forget Who I Am, you may even forget Who You Are, and we will both be lost. Then we will need another soul to come along and remind us both of Who We Are."  
 "No, we won't!" the Little Soul promised again. "I will remember you! And I will thank you for bringing me this gift ~ the chance to experience myself as Who I Am."  
 "And so, the agreement was made. And the Little Soul went forth into a new lifetime, excited to be the Light, which was very special, and excited to be that part of special called Forgiveness.  
 And the Little Soul waited anxiously to be able to experience itself as Forgiveness, and to thank whatever other soul made it possible. And at all the moments in that new lifetime, whenever a new soul appeared on the scene, whether that new soul brought joy or sadness--and especially if it brought sadness--the Little Soul thought of

Always remember,  
God had smiled,  
I have sent you  
nothing but angels.

**what God had said.**

**"Always remember," God had smiled, "I have sent you nothing but angels."**

P.S. Ciao, Garibaldi (Eleanor loved it when I called her this name, it was our secret, a secret code for transmitting affection). I hope to see you again.  
Forgive me, my Friendly Soul.

# ANGEL OF THE AURORA

## BY FATHER ADRIANO

Now that you are amongst the Angels  
In the Garden of Eden,  
Dressed in pink and blue with a side belt  
And hems of gold,  
Can you still remember your days on  
Earth Eleanor?

Your enchanted house  
Down there in the greenery  
Amongst birdsong  
And the geese dressed in white,  
The flowering hawthorn.  
The moon's rays  
Polished and clear in your nights.

The picnics on the grass next  
To the Fig tree,  
Sparkling drinks, sandwiches,  
Sweets and meringues:  
The squeals of delight and the happiness  
Of many dear friends circling around you.

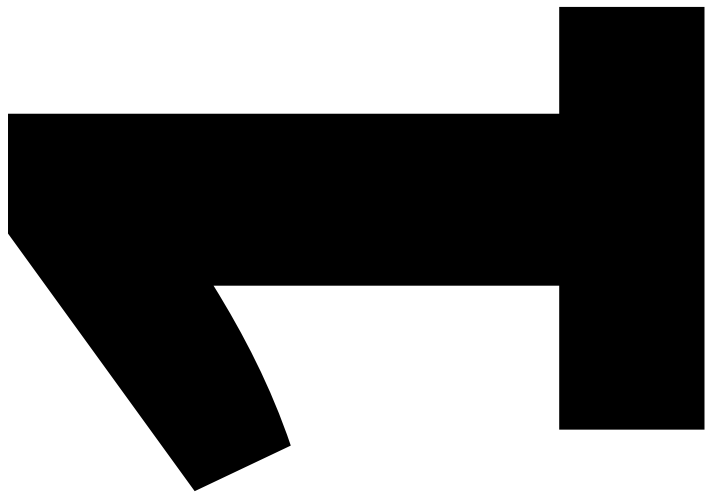
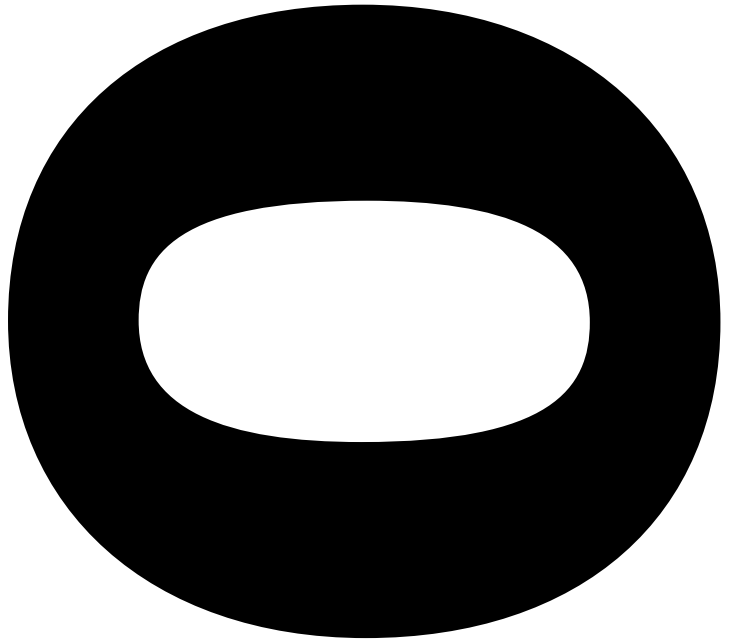
An angelic smile,  
Oh! And your arcane tears,  
Cornflower blue eyes  
Streaming with joy  
Or maybe melancholy,  
Like a rainbow bound  
By rain and sun!

Can you remember at the theatre  
The happy recital  
With the joyful Ulrike  
Water/earth/fire/air  
Wrapped in your costume,  
You a multi coloured fire,  
Protested in high?

Now, in the new kingdom  
Stationed in the morning  
To preside over the dawn,  
Defend us from the dark,  
Clothe us in stars  
And launch our flight  
Up there towards the great day.

Larks amongst the myrtles,  
Fireflies amongst the stems  
Of earth and new heavens,  
Will sing in hosts  
And garlands of light,  
Woven for ever within celestial  
Rounds.

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THE FUNERAL

# BERNARD'S EPILOGUE

"Whereof one cannot speak thereof must one be silent"  
Wittgenstein

I have been reluctant to contribute to this volume. The only thing worth saying about Eleanor's life is that it was horrible. True she was a person, behind her disabilities, of high intelligence and remarkable force of personality, but other people benefited from that, not Eleanor. Her intelligence served chiefly to make her life more difficult. A few days after her death Dr Martinelli, director of intensive care in Urbino, stood by her body and said, 'Ha sofferto.' [She suffered] Nothing I say here will improve on that.

These reservations have led me to present for publication something already written: an extract from a letter sent to a friend shortly after Eleanor's death:

She died on the twelfth of January slightly before 6.30 p.m. in the presence of Giuliana, Martin and myself. In narrow terms she died of pneumonia following influenza. Needless to say she died of a lot of other things as well. She was fortunate not to have died in 2003 and I really do mean fortunate. Once she was immobile incidents which caused problems for her, quite as much as for other people, were no longer possible. At the same time the frustration behind her difficult behaviour was replaced, because it had to be, by resignation. She was happy as she had not been before. In the period before her death there were, I think, indications that this period too was coming to an end. In 2003 Giuliana predicted that Eleanor would live as long as she wanted to and by the time of her death perhaps she had done so.

Does it seem morbid to write of funerals? Let me, because I want to. A mass was held a couple of days later. She was a well known figure locally with, for obvious reasons, lots of institutional connections and the church was practically full. Two people came from Pescara, one from Venice and one person, who knew Eleanor well and whom we had telephoned immediately, even came from England. The celebrant was a Franciscan friar involved in various ways with the local handicapped. He normally goes round in jeans but turned up at the house in full dress uniform even before robing. A fellow of St John's read the lesson. [Our son, Eleanor's brother Martin, at that time a junior fellow of St. John's College, Cambridge].

We took the coffin the following morning for cremation in Faenza (just south of Bologna). There had to be a delay of some days and then we took the ashes to England.

On this last Italian bureaucracy did us proud and I mention this because there was something elegiac, even caring, in its completeness; it seemed a kind of final, climactic salute. The British consulate and the Mayor



(Eleanor and Martin)

of Urbino gave their approval and we drove from Faenza to Ancona airport with a document stating the name of the driver, the car registration number, the flight number and even details of our continuing journey in England (to the churchyard of St Mary le Ghyll, Barnoldswick, where we assembled the following afternoon). The ashes were to be interred close to those of my father in the churchyard proper, which is anglican, though catholic by ancient right since it is pre-reformation. The final ceremony, therefore, was not Roman but English, as English as can be with umbrellas and the Book of Common Prayer. Nine people were present apart from those officiating. On the way home, apologising for being sentimental, I made a detour to drive past the school of which my father was head. I said that I wanted to write about the funeral and while writing I have understood why. Most of us enjoy or experience weddings or degree ceremonies. The only major ceremony of public recognition Eleanor ever had was her funeral. It is right to make the most of it.

## MARTIN'S DEDICATION

Martin Worthington  
Teach Yourself Complete Babylonian  
Hodder, U.K., August 2010

This book is dedicated to the memory of Eleanor Marie Pierisa Parodi Worthington,

ahātiya ša itti ilāni (my sister who is with the gods), and, in gratitude, to her friends Nunzia, Francesco, Monia, Flavia.

Urbino, 12 gennaio 2010