

N o a

Medical analysis Positive / Negative

Chapter 1

Medical analysis Positive

This is the story/tale of two Noa. You may well ask – two Noa? Isn't it in the plural? Noa is singular! As my story progresses, you will easily begin to understand.

Noa was born on the 19th of December, 1980, and although her birth was a difficult one she was a perfect baby. Letters were sent all around the world to family and friends expecting them to rejoice with us on the birth of our new-born. She was quite simply the perfect baby. Like all perfect babies she had a healthy appetite for mum's milk, for isn't it the best milk in the whole wide world? She slept when expected to sleep, ate when expected to. All of her bodily functions were perfect. Our friends and family were happy for us. Everything seemed just perfect.

After two months, it was noticed that Noa was slow in developing. "Nothing unusual," we were told. She'll be as normal as all other babies – you'll see." But Noa wasn't normal as other babies: She was slow in developing her motor skills, and by the time she was three months old, although she could raise her head, she wasn't capable of holding it still; it would rock from side to side. She was also incapable of fixating her eyes. They seemed to wander all over the place. She didn't seem to see anything, almost as if she was blind. But she wasn't. It was becoming evident that something was definitely wrong. What was wrong? Nobody seemed to have an answer for us.

Our family doctor didn't know if anything, indeed, was wrong. "She'll catch up," was his answer. Sarah, the nurse, **was** worried: She was worried that Noa was unable to hold her head upright. Professor Naomi Amir, a close friend of one of the kibbutz members, came to visit. She was a specialist in paediatric neurology and was considered a leader and pioneer in this field. Whilst staying on the kibbutz she was asked if she would take a look at Noa and give her opinion as to what she thought Noa might be suffering from. After she'd checked Noa and made her deliberations she thought that Noa may have the disease called Canavan Syndrome, but to be absolutely sure, Noa would have to go through a biopsy of the brain tissue. Eventually, she was to be proven correct in her prognosis. She didn't go into any full explanation of what "Canavan" is, and then, too, maybe she was wrong. Anyway, it would not be wise to create something out of nothing. She didn't want to be the cause of any panic.

I won't say that our Noa didn't progress. She did, but very slowly. After a certain point no more progress was observed at all. In spite of her slowness, Noa was the happiest child in the world. She laughed out loud a lot and at every opportunity.

If only ... Noa

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If only ... Noa

Chapter 2

Medical analysis Negative

This is the result of wishful thinking or day dreaming of what could have been of Noa had she not been afflicted with the terrible disease.

Noa at two months was the happiest and healthiest child on the planet. At every opportunity we took her outside the house into the early spring sun, and already she had two beautiful glowing red cheeks. If the sun wasn't too hot we took her outside naked, to save her the inconvenience of wet nappies. Pampers hadn't hit the shelves yet. Noa followed us with her lovely brown eyes and laughed readily when the occasion presented itself.

At three months she was pushing up and getting a better view of the world. She loved being showered or held in the bath. What a happy child. Noa didn't cry often, but when she did, boy did she know how to cry! Her lungs were the best developed part of her body. We were forced to buy the store's monthly supply of ear plugs.

She loved being pushed around in her stroller, and as soon as she was able to sit, the world took on another aspect, much more exciting. The colours, the noises and the smells, especially around the cow sheds -- she loved it all. She pointed with her tubby little hands at everything. Everything interested her, especially cats, dogs, birds and cows.

Noa refused to take part in the obligatory afternoon nap; it was as if she felt she might be missing out on something. As soon as it got dark in the evening she was hardly able to keep her head upright. As soon as she was laid down in her cot, she would be out of the world in a matter of seconds. What a pleasure she was. She was the easiest of babies.

Noa
Chapter 3

It had been decided by the nursing staff, after consultations with medical experts in Jerusalem, that at the age of one, Noa would be put through a series of medical tests to determine, once and for all, what exactly it was that afflicted her. On purpose I do not say what she is suffering from! Noa did not suffer at all from her affliction. Of course, she didn't realise that she was ill, and maybe because of that she remained the happiest of babies.

The journey for us to Jerusalem was a whole operation. We had never travelled with her outside the Kibbutz, and now we would be gone for several days. The stroller, the nappies, food -- everything had to be packed into the car, everything we would need for at least a week away from home. We were lucky enough to have a Volkswagen van with lots of room.

Fortunately, we had a friend whose Italian connections in Jerusalem enabled us to reside in a large and beautiful apartment – Slam Bang in the centre of the city. The apartment was five minutes walk from the hospital. Noa was operated on and a biopsy taken from her brain, after that, she convalesced in the hospital for a week. During that time, when there was nothing else to do, we got to know the city – walking along its lovely, picturesque streets, shops and markets.

A biopsy of brain tissue was needed for a conclusive answer as to what Noa had. In those days that meant cutting a hole in the side of her skull, taking a portion of brain tissue, and putting it through a series of Gawd only knows what procedures. When we first saw her after the surgery, she had an enormous bandage swathed about her head. We were genuinely worried as to how to manage: how to bathe her and even how to hold her.

The hospital staff was a great help, instructing us what to do, and how to do it. The first time we witnessed the change of her bandages, we were told that the hole created in the side of her skull had not been closed up; only the skin was sewn back over the hole. When we worriedly asked what would happen with the hole, the answer given us was that in the course of time it would close itself up with new bone growth. Through the hole in the side of her skull one could observe the blood vessels palpitating. It was all very disconcerting, and yet eventually we were able to ignore it especially when her hair grew back and covered that part of her head. It took many years until the hole closed up completely. After her hair had grown back it was impossible to tell that she had gone through such an operation.

The final results took quite some time to come through. When they did, we were already reconciled to our situation. Life for us with Noa continued on as usual. The results brought with them the learned observation that children with Canavan Syndrome do not live much longer than three years. The disease can only be contracted if both of the parents have the same mutated gene; we obviously had it. We learnt also that Canavan syndrome is a disease found only in Ashkenazi Jews; usually they or their parents or someone along the family line, came from North Eastern Europe. We were told also that there are over two thousand genetic diseases and quite a lot of them equally as debilitating.

As Noa grew, we took it in our stride. She was a part of our lives, and we took care of her accordingly. She became our focus in life. Not once did we bring up the subject of making our own lives easier by handing her over to some hospice or whatever. There were suggestions by well-meaning people telling us, that a hospice would be a better option for us, and we could then get on with our lives. We rejected such advice. We already loved her too much to do such an objectionable thing. We wanted to make Noa's life as pleasant and enjoyable as humanly possible.

Living in a Kibbutz made our load a lot easier than if we had been living anywhere else. Our every day life was simple: In the morning before we went to work we would hand Noa over to a child-care person in the kibbutz kresh, (children's house), where she was lovingly cared for. We, Noa's parents, collected her for home after finishing our day's work.

I must admit that at the beginning we were a bit shy going around the kibbutz with a child who was so obviously invalid. But we quickly overcame our inhibitions, and Noa accompanied us everywhere and to every event. She was, after all, a part of the family.

Very soon it became evident that Noa loved music, and music could be heard in our apartment all day everyday, sometimes from the radio, sometimes from the gramophone.

Noa had three siblings, but because of the age gap (the youngest being eleven years older); it was hard for them to relate with her. Noa's third birthday came and went, and she was as healthy as any parent could wish for their child - except for - her affliction. She was rarely ill, never had any of the dreaded children's illnesses, and she remained unusually healthy all her life.

Noa Chapter 4

By the age of thirteen months, Noa had been cleaning the floor with her crawling for the last six months, and now she was making her first tentative steps at walking. Two days later, she was walking, walking and walking. She insisted on walking everywhere, and from then on she resisted being picked up and carried anywhere. She wanted only to walk. It was impossible to ignore her as she approached, because the first month or two of her walking she would gurgle or just plain scream with joy, as if to say, "Look! It's me! I'm walking. Here I come!"

It wasn't all joy, this walking business. At first she wasn't all that stable on her tiny chubby legs, and every so often she would fall. And oh! What a tragedy! Her tragic crying was even louder than her usual crying.

One time she fell, and the poor thing scraped her knee, and after seeing her own blood she started bawling her head off. It was unbelievable! What a racket she could kick up, but luckily it didn't last long. A man riding a horse went by, and suddenly distracted her, Noa looked up fascinated. Within a fraction of a second she switched from crying her lungs out, to gurgling with joy at seeing the horsie.

From the moment she could walk, that was IT. Nothing was impenetrable or out of reach. With everything within her reach, she was in continuous danger of electrocuting herself, drowning, and or doing herself other serious damage. We had the feeling that keeping an eye on Noa was our sole mission in life. I bought a camera and started taking numerous photographs of her. Often enough they were of Noa in some compromising situation, like the time she was covered from head to foot in mud and reaching into the fridge to grab at something. She was a handful, and we loved her. Quickly two years went by, and then the third.

From the third year of her existence, she discovered that she wasn't the only person in this world. She realised that we cared for other people beside herself. She understood that her two brothers and sister also had a part to play in her life. The youngest of her siblings was Benny, and he was by then fourteen years of age. She became his personal leach. She loved just holding his hand and walking alongside him. Both Benny and Danny, the older brother, were players in the local water polo team and they were big, strong and tall. There was nothing she liked better than being with these, her own personal mountains, who quite simply towered above her. She loved her sister Noga as well, but Noga was just before enlistment into the army and had other things on her mind than playing with Noa.

At three, Noa had already learnt to swim, and much of the summer months were spent in the pool with her parents. Or she would accompany her brothers to a water polo training session. She was also took part in swimming lessons which were held in the mornings with other children from her children's house. She was in her element, in and near the water. She

was without a fear in this world, and she could be heard all hours of the day squealing with joy. Her mother said that Noa was THE Absolute Tomboy.

Talking came easily to her, and by the age of three she had become a regular little chatter box. Until she laid her head down at night she was continually saying something or asking questions. It was impossible at times to keep up with her.

Noa had only one doll, a filthy and torn rag doll that she would not let us throw away, nor would she let us buy her a new and cleaner one. Apart from the rag doll, the things that really interested her were frogs, bits of sticks and rope, and various activities like clambering over things of all shapes, sizes and heights.

Age three, Noa is the owner of one dress. She should have been proud of it, but she hated it. Usually she could be seen wearing short trousers and a filthy, torn tee-shirt. It's not that we didn't clean her clothes; it was just the same old thing of not being able to keep up with her. On her feet at all times, most often running, she was always barefoot.

One day, I hung a thick rope with an enormous knot on the end, from a branch on the tree outside the house. From that moment on she had another challenge, and at the ripe old age of three and a half she'd made up her mind to climb all the way up to the top of this three-metre rope. We forbade Noa attempt this unless an adult was outside with her. That caused her to nag us: "Pleeeese come outside and let me climb the rope." If she wasn't climbing the rope, she'd swing on it. Holding the rope between her legs and sitting on the large knot she'd swing for hours. Eventually, she reached the point where she could swing level to the branch holding the rope. Every time she reached the apex of her swing, on the way down she'd yell out "Y E S S S." Noa was as wild as they get, and yet every evening she'd cuddle up to whoever was putting her to bed and demand a story, often falling asleep before the end.

Noa Chapter 5

From the age of thirteen months Noa made no more progress at all. It wasn't very long before slow and incrementally regressive changes started taking place. We were

continuously on the lookout to make Noa's sitting arrangements at home more comfortable. She was completely dependent on us for everything; the only thing she was capable of at this time still was chewing her own food. A capability she was also soon to lose.

The guy in charge of the metal workshop on our kibbutz spared no effort in making a super duper stroller especially for Noa. More than once it was changed, and to such an extent that the final product was a superb piece of equipment. The only original part of the first push-chair was the handle bar. The end product, after many changes to the frame and the wheels, was a comparatively light stroller made mainly of aluminium. It had big wheels encompassed with soft tires that didn't need inflation; it fitted Noa like a glove. For travelling, it could be folded up and taken apart and used as her own special chair. The stroller was so versatile that I had no compunction about leaving the concrete paths and even going out into the fields with her. Noa just loved all the bumping around on uneven paths.

One of the functions I would take Noa to was to watch her brothers playing in water polo matches between our local team and visiting teams. I would sit there with her in my arms, or she would be sitting in the stroller.

Once, as we were watching a match, I fed her food prepared before-hand. Her brother Danny was participating in this game. As was usual in these matches, the spectators took more than an active part in supporting their local team, but at one point in this particular game, a dull and less exciting part of the game, the crowd was almost silent. I was watching the game and at the same time, without looking at what I was doing, putting morsels of food directly into Noa's mouth. Suddenly Noa clamped her teeth down on my finger; I let out a yell and all the crowd looked up at me. I felt such a dummy.

Her clamping down on my fingers was another symptom of her problem: She was slowly losing the ability to chew her food. Instead of moving the food around in her mouth and moving her jaws from side to side, she eventually stopped even the up and down motion. We were told that eventually this would happen, and that shortly we would have no option but to feed her through a pipe, (*nasogastric or orogastric tube*), a feeding tube going either up into her nose and down into her stomach, or a tube going directly through the stomach wall. We dreaded it, but it was an inevitability that was impossible to avoid. It was left up to us to decide which method would be better for Noa. We decided upon the nose method, there seemed to be less complications of possible inflammation.

I mentioned earlier that Noa was a happy child, and it was easy and pleasurable making her laugh. Although she was unable to focus her sight, because her eyes wondered all over the place, it didn't prevent me from finding ways to make her laugh, I would run towards her calling out words and sounds, and she'd burst out laughing, so much so that sometimes we were frightened she'd choke: That never happened.

At about the age of three, for some inexplicable reason, she stopped sleeping most of the night. We'd lay her down in her cot, she'd fall asleep, and in the middle of the night she'd wake up. Fully awake, she'd start laughing. Invariably, I was the one who'd

put her in her stroller and start pounding the kibbutz paths in the middle of the night. There was no use in both her mother and I not sleeping. Noa was as happy as could be with this new arrangement. And I, like a zombie, would be walking around half the night. Eventually, she grew out of her midnight wakings.

I mentioned that Noa loved hearing music. One time, a young woman who was an accomplished violinist, visited us. We asked her if she would play something for Noa. Noa was in seventh heaven. She seemed to know that the music was being performed just for her. She stretched her limbs almost to rigidity and smiled, gurgled and laughed; she loved every note.

Another time I was visiting a music teacher friend of ours who was teaching music to a young boy. His instrument was a saxophone. The teacher said to me, "Ron, you had better hold on tight to Noa, the loud noise may frighten her." The dead opposite happened: She loved it. She was in ecstasy over every noisy and off-key note of it. Noa had her musical preferences. She loved classical, children's, and especially baroque music. Oddly enough, though, when once I played for her a record of English Nursery Rhymes (I'd had it sent over especially from England for her); it did absolutely nothing at all for her. I am sure it was not the words, but maybe the cadence . . . Anyway she definitely did differentiate between different types of music. That should be something worthwhile studying!

Noa Chapter 6

Between the ages of three to six she turned into a little monster: Constantly on the move, rarely walking, usually running at speeds unattainable for us. Running, jumping or skipping were a part of her propulsion methods. She was on constant overdrive. Once, when I came to her children's house to pick her up, the day-care person said to me in exasperation: "I can't keep up with her. There isn't a fence that can keep her contained, and I blame you for that. She can climb over anything. Now go look for her yourself!"

Noa had gone home on her own, but she'd been side tracked and brought home a dead kitten she wanted me to bury. Our garden was a mass graveyard for kittens, birds and other creatures, not all of them warm-

blooded. We had a whole section of the garden, *graveyard*, set aside for dead flies.

Noa had learnt quickly to do away with the side wheels of her bicycle. Now, if she wasn't running, she was flying all over the place at top speed on her bike. She nagged me blue in the face to add a small cart behind her bike so that she could add more dead animal bodies, stones, feathers and sometimes just plain wet mud. I found out one day that through the influence of some TV film she'd decided to make a mud brick house and live in it. Like I said, she was continuously on the go.

Noa had friends of course, mainly boy friends; she just fitted in better with boys. But she was a league all of her own, a leader, inventive and adventurous to the point of danger. I must admit, though, that most times she did know when to back off when she was in real danger.

One day I came home and found Noa in the garden playing or teasing something in the grass. When I got closer I saw it was a snake, a poisonous one. I came up from behind her and grabbed and pulled her away just as the snake was about to strike. I yelled at her, "Noa, you can't play with snakes! It has to strike you only once, and his poison can kill you, unless you get to the hospital immediately." As an after thought I added, "Then they will have to given you an injection." I said that because I knew how much she was frightened of injections.

"But Daddy, I saw Danny doing it; he caught one and put into an aquarium. I did, Dad. I wanted to bring another snake for Danny."

"Well, Noa, your brother Danny is crazy, and I don't want you copying him. At least he has had some experience catching snakes, and he has been lucky up till now. Don't you ever let me catch you doing it again? Promise?"

"Yes, Dad."

It helped up to a certain point. I never caught her trying to catch snakes again, but she went after mice so that she could help Danny feed his snakes. What a girl, and she was only six and a half! We needed eyes in the back of our heads.

Noa was going to school now. Although at the beginning she refused to go, the refusal stage lasted only a couple of days. During those initial days I had to accompany her to school. When I saw she was settled in, I discreetly

took my leave. She made it hard for me, though. For two days I left her trying out her lungs on the school teacher's ears. On the third day of my accompanying her (again I was dreading the leaving scenario) she suddenly turned round and said, "Daddy, you can leave me now. My friends have asked me to play with them."

After that she was on her own, not even needing my company up to the school gates; she had her mates all around her all the time.

At school she started learning things that, somehow, were not connected with tearing around at breakneck speed, climbing up to impossible heights, and tending dead and live animals. She learnt about culture. There are musicians in the family, and her mother has an ear for perfect pitch. So she brought home her first and only recorder; every day she then practiced her music on our delicate ears. It was a terrible period. The only reason she didn't persevere was that at the end of the school term she wasn't allowed to play in the school concert. But neither she nor her music teacher gave up on her so easily. The teacher said, "So what if she's tone deaf. Maybe she should try a percussion instrument!"

That was an even bigger mistake. One day the teacher gave Noa a small drum. She loved the noise she could produce with it, and although she was already able to follow written music, it was one cacophony of noise, nothing at all related to music. Inside the house, things were beginning to fall off the walls, and our poor suffering ears were taking a real thrashing. So we asked Noa to play outside, which she did. Then our neighbours started complaining.

One day. Noa was present when one of the neighbours was making a justified complaint. Noa then decided to get away from it all, and with the drum tied around her neck and the drumsticks held in her teeth, like an old-time pirate boarding the enemy's ship, she climbed to the top of the tree outside the house and played away to her heart's delight. After an hour of that, the neighbour whose window was directly opposite the top of the tree's branches, came down to us and said. "If you can't do something about the bloody noise, then I'll cut the tree down with the noisy brat in it."

I'd also had enough of it. Angrily I climbed the tree. It was with great danger to myself and the little girl at the top. I weighed a lot more than she did, and was in danger of breaking the branches that both she and

I were on. Somehow I reached her, took the drum from her, and threw it to the ground. Noa started crying just as only Noa knew how to cry. I tried to grab hold of her and bring her down with me, but it was impossible. So I left her there. She cried, she screamed, and she cried some more. Although an emergency collection of friends, parents and child-advisors stood at the bottom of the tree trying to cajole her into coming down, nothing worked. She came down an hour and a half later when it started getting dark. She was afraid she would not being able to see the branches in order to climb down. No doubt about it: We were too harsh on her. When she reached the ground she took the drum into her hands (the drum had suffered only minor scratches), and sulking went early to bed without eating a thing.

The following day, she held the drum firmly in her hands. No one was going to take the drum way from Noa. She came home, had a bite to eat, and went to the cow sheds where she played her music for the cows. She really did love the cows. We and none of our neighbours had anything against Noa playing her music for the cows; it was far enough away from human habitation as to not interfere with daily life. At first, the workers in the cow sheds were amused by it all. Noa, poor thing - everyone was against her. A week later, the guy in charge of the cows came complaining to me that the cows had been giving considerably less milk since Noa had started playing her drum there.

Almost a wits end, I went the next day to the music teacher to tell her about Noa's unsuccessful music career and the damage it was causing. After a long talk, I must confess I was ready to give the teacher a big wet kiss. She'd come up with the perfect solution: Noa was to learn conducting. From then on, everyday, Noa could be found everywhere waving her arms around to music only she could hear.

What surprised us most was that, at the culminating recital at the end of the school year, it was Noa who conducted the school orchestra all on her own. That same evening, at the end of the evening's activities, I went across to the music teacher and without warning gave her a big wet kiss on both cheeks. When her husband, who was standing at her side, asked his wife what that was all about, she told him, and he could be heard laughing all the way to the car park.

Noa

Chapter 7

We were continually on the alert for changes, sometimes quite subtle ones that were happening to Noa. Not that we were able to change anything, but we wanted as much as possible to make things easier for her. From the age of about six on, although she was growing at a slower rate than healthy children, she was still growing and getting heavier. It is not that Noa was ever really heavy, but it made life for us gradually more difficult. When an adult picks up a six-year old child, the child helps out by clinging to the person, thereby spreading its weight about the adult's frame. With Noa, we were picking up a dead weight: She didn't cling or hold on at all. Her whole weight was on our backs and arms.

It was almost a maxim for us, finding new and other ways of making her life easier. At home, we would sit her in an enormous cushion-type chair and to stabilise her head so that it would not turn round to one side we invented a special type of pillow. In the summer, when it became very hot, we had to make sure she didn't become soaked in sweat from continuously being in the same position, either sitting or lying down. Often she was naked, apart from her nappy.

In spite of all this, Noa was consistently a happy child. We were very lucky in that respect, having been told by experts that children with her malady would often cry the whole time. That was something Noa never did.

She was getting older, and yet she always stayed with the same age group of children. It was becoming more and more difficult for the child-care people to care for her in a children's house which was full of other children, all with their own needs. The problems it was creating were brought up before a committee: It was decided that Noa needed a special carer just for her. Then we hired Sarah. She came from the town of Akko a half-hour journey from our kibbutz. We taught her everything there was to learn in caring for Noa and she stayed religiously with Noa till the end. Now when children were taken out for a walk to the cowshed, the orchards, or just about the kibbutz, Noa was there with them, and Sarah was there just for her. Occasionally Sarah went on holiday or was taken ill, and it was up to us to take time off and be with her; then a solution was found for that as well. A lady whose job it was to work in our Old Folks Home was usually given prior warning, and would take over from Sarah whenever the need occurred.

Everyday, one could see a whole bunch of toddlers walking about the kibbutz with their child carers herding them from one place to another, and Noa with Sarah going

along with them. Noa was part and parcel of the group. The small children accepted Noa as one of them even though she wasn't participating in any of their activities. Often a child could be observed going up to Noa and giving her a hug and a kiss, or just talking to her. Noa was always there for birthday parties and holidays. She just loved having the children around her and, of course, loved their music.

Sometimes, when one of the children would tire, the carer would sit the child on the stroller with Noa. Noa didn't mind. Sarah and Noa would accompany the children on their excursions to the orchards, and often on the way back, the large cloth bag attached to her stroller would be full to bursting with avocados, or oranges, or even lychees. In the summer months, because of the excessive heat and glare from the sun, we arranged for a very special parasol to be fitted to Noa's stroller.

She was a mass of contradictions, our Noa. She had this terrible debilitating disease, and yet she was hardly ever ill. Our local Doctor said to us more than once, "If all the children I deal with here on the kibbutz were as healthy as Noa, I would be out of work." No doubt about it. Unbelievable as it may seem, physically, she was as strong as an ox -- and yet she was unable to do a thing. She was completely dependent upon us and our constant everyday loving care. On top of this she was happy and full of laughter. Go explain it!

An additional problem was slowly developing: Her legs were becoming spastic. Changing her nappies was becoming increasingly more difficult. Her legs were like two boards with a tendency to cross over one another. To separate her legs for nappy changing without hurting her was becoming increasingly more difficult. Her hands also were becoming spastic, at the beginning only at the wrists. Her hands turned inwards, and it was impossible to straighten them without causing her pain and possible damage.

There was a period when Noa was having problems with liquid collecting in up her throat. Although we did not look upon this as an illness, we would nevertheless take her to the clinic where a special suction unit removed the liquid from within her throat. We had to loosen up the phlegm by tapping on her back, like it is done to children with cystic fibrosis. I suppose because all these things were not piled up upon us all at once; they were coming at us one by one, so we slowly we became accustomed to these blows, one by one.

Then came the day, and there was no putting it off, when we had to decide how she was to be fed from now on. There were the two possibilities: A pipe could be inserted directly into her stomach through the wall of her belly. And with the aid of a syringe, food we'd liquefy could be fed straight into her stomach. The other method, which eventually was adopted, involved a long, thin transparent tube that could be slid through her nose down into her stomach. Delivering her liquefied food in this way, would make it easier to prevent infections.

She was fitted with the nose tube; at the start we were a bit wary of having to change the tube ourselves. It seemed so unnatural and difficult guiding the pipe up into the nose and down into the stomach. In time, though, we accomplished the knack of doing it with an almost envious fluidity. Although, with the help of the nurses, we'd learnt to do it this really very mechanical skill, we eventually became more adept at it

than the nurses. The tube had to be changed every so often; despite our rinsing it thoroughly after every meal. The plastic tended to retain some food stains, and that was considered unhealthy. The changing of the feeding tube was unpleasant for Noa, but we'd got it down to an art it took us no more than a second or two. We bought a mixer especially for pulverising all the food we fed her. One of the basic foods she was fed was avocado. We made sure to put some in the mix with vegetables, fruit, and meat. We tried to make her food as healthy as possible. Often I would make too much – on purpose – and eat the rest myself; it was quite yummy.

I may be mistaken about the date of events, but at the age of nine, because she was becoming increasingly spastic, it was increasingly difficult to dress Noa, especially to change her nappies. We sought advice from our doctor. He also didn't know of a proper solution for our predicament, so he sought expert advice. A little while later he came back with what sounded like a terrible solution. The solution was to operate on both of her hip joints disconnecting them both. It was explained to us that because she never uses her legs it will be of no inconvenience for her. We saw no other alternative; and no other solution was proposed to us. I don't remember the operation except that Noa came out of it with flying colours. She was so strong that she was able to over-come everything thrown at her.

In the beginning, after the operation, it felt weird holding her with her legs just dangling down without any semblance of control. However, she had never had any control over her legs or, for that matter, any part of her body. Now, without a doubt, she was a lot easier to dress. Many years later, I forget for what reason, she was x-rayed and the doctor in charge raised an eyebrow and asked accusingly, "What have you done to her legs?" Of course he could not have known everything she had gone through. Despite all the difficulties that confronted her year after year, Noa always bounced back quickly; after a short time, all was laughter again.

I often wondered if she understood anything said to her: Is there anyone in there? Many years later my doubts about Noa's comprehension were put to the test.

Noa

Chapter 8

Noa is now seven. Thank God she no longer feels the need to play any musical instruments -- not in the house or in the garden or anywhere. But she religiously practices her conducting. Her music teacher fails to understand this. Usually a person who conducts has an ear for music, and quite often plays some instrument. But not Noa; she cannot play a musical instrument for the life of her. She does not hear herself playing alongside anyone else. She does though conduct comparatively well. It seemed to me

she just loves flinging her hands about. Later on we came to realise that Noa really did hear the music in her head, and as odd as it may seem, she conducted with perfect timing.

At the age of eight and a half, Noa was in the throws of preparing for a big school concert. She practiced everywhere. Friends and even strangers were getting used to seeing that little girl throwing her hands about in a frenzy, with her head thrown back, humming something in no special key. Two days before the concert, she was up the tree outside of the house conducting her imaginary orchestra to the attention, I think, of a kitten on a branch opposite her. Suddenly, the kitten jumped from its branch onto Noa's lap! Noa took fright and fell backwards from the branch and landed badly breaking her leg. She didn't realise that she'd broken her leg, and for a change, crying softly, limped into the house. Her mother, realising immediately that this was more serious than just a few bruises, called the clinic. Noa was taken to the hospital where she had her bone set. Out of hospital the following day, and she was in a push chair. She didn't like it one bit. That same evening her music teacher came round to see how she was doing. What she saw prompted her to tell Noa that she would relieve her from the task of conducting, and would herself take over conducting the concert for her. In spite of being very tired and almost groggy, Noa refused to give up the baton. She said she would do it even if she had to do it sitting down. The teacher relented.

The opening moment of the concert, when the conductor customarily strides onto the stage, was a bit different this time. Noa was wheeled onto the stage and awkwardly took a bow. She then wheeled around to face the musicians and conducted for some twenty minutes. Although Noa was not able to throw herself into the mood of the situation as much as she would have liked, she was **THE HIT** of the evening. When she turned to take a bow, she forgot herself and tried to stand up. Luckily one of the young musicians near her caught her before she fell on her face, and sat her back in the wheel-chair. We brought her home flushed with triumph and as happy as a lark.

The push-chair was hardly an impediment for her: The following days she was flashing around at top speed around corners, even down stairs. She

was like a bloody maniac let loose. Three days later she was given a walking cast. That also did nothing to slow her down.

Of course, Noa's plaster-cast was highly decorated by almost everyone writing their names, poems and pictures. For a week she hobbled around with a packet of coloured crayons, asking everyone she saw to write or draw something on her cast. When the time came to remove the cast it was battered beyond recognition. I am sure that she was upset to see it removed.

By the age of nine, Noa had managed to break her wrist and crack two of her ribs. But nothing could stop this bundle of energy. It's not that she was one of those people prone to accidents, or so I maintain. She quite simply was everywhere, all the time, and doing everything at breakneck speed.

She kept up with her conducting, and we were told that she was a natural at it. Where did it come from? Her grades at school weren't fantastic, but she was quite good at some subjects. She liked learning English, and within a short time she was the best in her grade and the two grades above her. Later on we learned that she was one of those lucky people who have a flair for languages. She muddled by in maths, and the same in most of the other subjects. But as for physical sports, she was a tornado! She was on the school running team (as might have been expected), excelled in all the ball sports, and insisted on taking up judo. She never seemed to tire. At least that is what her teachers said of her.

We saw the other side of these physical achievements. Come seven or eight in the evening, Noa was ready to collapse. If she wasn't in bed by nine o'clock, I often would have to carry her inert, sleeping body to bed. If she got into bed early, it would be my job to tell her a story, always a different one every night. She loved my telling her stories. One day I saw her wedged between branches up in a tree telling a cat a story about a dragon. I doubt if the cat was all that impressed but at least it stayed on till the end of the story.

Noa loved the big outdoors. With a small rucksack on her back, she enjoyed going on long hikes. Hiking was first discovered when her brothers took her on a one-day hike. She came back covered in dust, dirty smudges

all over her face and arms, a few tears in her clothes, and one hell of a smile all over her face. After that she would nag me or her brothers to tell her when the next hike was to take place. In time, we taught her to use a compass and to read a map. It was a whole new world for her, and she soaked it up like everything else she liked doing.

One day, the drama group in school was short of a girl dancer. They approached Noa, and of course she agreed to try, though she wasn't exactly a natural at dancing. When she discovered that it meant wearing a skirt or a dress, that was the limit; no way would she wear any silly girly clothing. Yet, although she was very much a tomboy in almost everything she did, she was in some things very much a little girl. At such times it was hard to brand her.

Noa wasn't a picky eater, and like most of us she liked certain things above everything else. One day, whilst we were out on a hike, I brought some chestnuts. She'd never seen or heard of chestnuts, let alone taste them. They aren't grown in Israel; they are imported from Turkey. It was late, and we were sitting around a small bonfire. Noa was already in her sleeping bag, half asleep when I woke her and said, "Noa, taste this. I think you will like it." Wow! Did she like it! She loved it and demanded more. I'd only brought a pocket-full of chestnuts and she finished off nearly all of them. She discovered the delights of pushing them into the embers, then raking them out and the process of burning one's fingers whilst trying to peel. She loved the whole process. This was better than marshmallows over the flames.

One day, after breakfast, she suddenly became very ill, vomiting and crying in pain. We rushed her to the hospital where, after a few anxious hours, she improved. The doctor in charge said she might have an allergy to some food, and he thought it would be a good idea for her to go through an allergy test. He asked what she had eaten that morning and we tried to pin down the allergenic food source. It wasn't very hard to pin it down. She'd eaten all the same things she ate every breakfast, except for one item of food that was new for her: It was halva. We were informed after the allergy test that it was almost certain that the sesame seeds that make up the halva were the cause of her allergy. She was informed as to the dangers of eating any food item containing sesame seeds. She soaked up the

information, and from then on whenever halva, sesame seed snacks or anything containing the seeds was offered her, she knew it was off limits.

On the day before her ninth birthday, both she and I were walking past the cow sheds when all at once we came across a butcher in the process of butchering a full size cow that was strung up on the rafters. The cow had taken a fatal fall and died almost immediately. So that her meat would not go to waste, she was being butchered on the spot. I would not have chosen to show Noa this process, but by accident we had come upon it. She was frozen to the spot as the butcher deftly peeled off the skin and started to cut off the cow's limbs and parcel up the meat. I explained to her what it was that we were seeing. She was very quiet. After what I thought was a judicial amount of viewing time, I said to Noa, "Come on, Noa, let's go back home." And she fainted. She was out for only a few moments, but I carried away her in my arms as fast as possible from the grisly scene. Nothing was mentioned about the affair, and she continued to sleep well at night.

Noa Chapter 9

The state of Noa's disease from between the age of nine to fourteen seemed almost stable. But although it was hard to discern easily, there was a continuous deterioration. Little things appeared that one by one made her and our lives that bit more complicated. She was, as I mentioned, being fed through a (nasogastric or orogastric tube), and now it was completely obvious that she would not revert back to eating on her own.

Each year that went by, Noa would stay in the same children's house although other children were growing up and going on; she stayed in the same place.

In the afternoons we brought her home, fed her, and did all that was necessary for her health and well being. Hardly a day went by that I didn't take her for a walk around the kibbutz. Sometimes I'd walk for an hour or even more. It was my time for reflection; often I'd walk and make up stories, usually children's stories. Occasionally Noa would star in the story and the following day I used to tell the story to other children.

At this time I was working as a child carer for nine- to eleven-year-olds. At those ages kids just love hearing a story. I remember one story I told the children: I told them that one day I was pushing Noa in her stroller, going down a path between fields when a flying saucer appeared above us. The story told of how they, the aliens, beamed us up, and we went around the universe with these highly advanced aliens, and they made Noa

better and healthy again. Until I reached the end of the story the kids believed every word of it. I worked with children for some five years.

Although unlike other children, Noa by this time was hardly growing in size. Yet it was becoming more and more difficult for Sarah and for us, her parents, to pick her up and move her from here to there. We were not getting any younger. It was decided that to make our lives somewhat easier we would have to find a solution for bathing her. In time we found a small factory, which was later on bought out by our Kibbutz plastics factory for producing plastic mouldings. We approached the people in charge and asked if they could take it upon themselves to make a bath especially for Noa's and our needs. They agreed, and the final product filled the bill perfectly. It was waist high, just the right length and width; it made a substantial reduction to the strain on our backs and also helped reduce the effort and energy spent on Noa every day. All these things: the stroller, the bath and a myriad of other things that were aimed at making Noa's life so much better were paid for by the kibbutz -- without once looking at how much it cost. We often thought to ourselves, how does a family living in town manage if they don't have the broad back of a kibbutz supporting them all the way? It was not easy for us, yet how must it be for families with a child with such an affliction and maybe other children as well to care for; they must go through hell just keeping sane.

As I mentioned earlier, Noa was hardly ever ill, yet occasionally things did happen that affected her health. I do not remember the exact date it happened, but it affected her well being for the rest of her life. One day Sarah her nurse/carer was preparing to bathe her. She undressed her and put her in the specially made bath already half full with water. It was filling whilst Noa was in the water. Sarah turned around for a few moments to arrange her clothes. When she turned back to Noa she realised something terrible was happening. Noa was convulsing; the water pouring in had for some reason turned boiling hot, and it was scalding her alive. Sarah immediately pulled Noa from the scalding hot water and realised that she had terrible heat burns over large parts of her body. Sarah immediately called the clinic, and within a very short time Noa was on her way to the burns section of the hospital. We were also notified and went immediately to the hospital. She had burns on her legs and back, but Sarah's quick actions saved the day. Noa was hospitalised for several days, I fail to remember for how long. Luckily her burns did not need transplants or anything as drastic as that, but she was burned over quite a large part of her body. What makes me shudder to this day is that Noa was unable to call out in distress or even cry. She just lay there convulsing. For me it is impossible after all these years imagining the agony she was going through. We did not blame Sarah at all for what happened; a mistake was made and it could have happened to us. Of course, measures were taken whereby this sort of thing could not happen again.

Although Noa eventually bounced back, like she always did, we noticed a change in her cognitively; she took less interest in things going on near her; she was less responsive to stimulations. She still laughed when I fooled around making her laugh, but less. She was becoming more and more apathetic.

Noa

Chapter 10

At the age of ten and a half, Noa discovered something that we'd tried to hide from her: the days her brothers went out on hiking expeditions. They would often take with them ropes, and with them add to the joys of hiking, climbing and rappelling down cliff faces. We knew for sure that if she found out, she would demand to take part. It was impossible to hide anything from Noa for very long. When Noa made this world shaking discovery, it was just as we imagined it would be; she demanded to take part. We came to an agreement with her that I would accompany her on her first trip, and that she would only be a spectator. We hoped that maybe she would be put off by the risk and the height of some of the cliffs. No way. The moment she saw her brothers like spiders going up and down cliffs, that was it. She would not be pushed aside; she demanded being part of this new game.

The next time we went on a hiking trip we capitulated. No ordinary person can understand the extraordinary pressure a little ten and a half year-old girl is capable of applying. She used all sorts of extortion and threats, and in the end we were left with no choice but to capitulate. After capitulating, we demanded of her brothers that they make a special harness suitable especially for Noa. The harness was made just like the ones they'd made for themselves, specially made so that it would be easy to connect with ropes.

As with all dangerous activities that included Noa as a participant, I would take the plunge first; no way was I going to allow my little girl to descend cliff faces without me trying it out first. I must admit the first couple of times for me the hardest part was the very beginning; just clearing the top of the cliff. After that it was clean sailing -- fun! For Noa it was fun from the very beginning. She loved every minute of it, simply couldn't get enough. She was insatiable. That was when I realised that my little girl was adrenalin junky. She was taught to jump away from the cliff face and

thereby be able to slide down the rope a lot more easily and faster. She was like a kangaroo, only gliding downwards. On her way down the cliffs she made little yells, screams of delight; she was going through utter ecstasy.

Within two months she had already descended some seventeen cliffs. After that there was no holding her back. I remember one particular outing whereby we rappelled down through the roofs of enormous man-made limestone caves, several kilometres south of Jerusalem. The caves -- thousands of them -- were excavated by very early Christians escaping the Roman Empire's strict laws of the time and persecutions of practicing Christians. The caves had been excavated by digging downwards and as they went down further and further so they expanded the width of their excavations thereby making bell shaped caves of enormous size. In some of these caves whole orchestras perform because the acoustics are so good.

Getting back to Noa, on one of her descents she was coming down through the hole in the roof of the cave, I was already at the bottom waiting for her. Standing next to me was a couple of foreign tourists, and like me they were staring up at her as she came down the rope towards us. When Noa had almost reached the bottom of the rope one of them said to the other, "Oh my God, it's a little girl!" They were astounded. Noa disconnected the rope from her harness like the little professional she already was - and as if it was the most natural thing in the world.

After some time, even that wasn't enough to give her the adrenalin fling she so much craved, she wanted to take part in climbing up the cliffs like all of us grownups. We refused to allow it, saying to her that it was much too dangerous; her arms and legs were not long or strong enough. This really was the limit, and we told her that under no circumstances would we allow her to climb. She was told quite emphatically that she'd have to wait until she was bigger. Undaunted, she worked out a strategy: She made out as if she was sulking whilst looking up at those climbing a cliff. We were terribly mistaken. She wasn't sulking at all. She was studying our moves as we slowly made our way up the cliffs. Then one day, on one of our trips, we'd arrived at a rather formidable cliff of some seventy metres height and decided to rest at the bottom of the cliff before trying out our climbing prowess. No one was aware of what Noa was up to at that moment. Suddenly we heard from half way up the cliff, "Hey daddy, look at me!"

I almost fainted on the spot. There she was halfway up the cliff without ropes and clinging to the cliff-face like the monkey she really was. Immediately the most experienced climber of our group started up after her, carrying an extra rope for her. How she got so high was, at the time, beyond me. It was a certainty that soon she would be stuck and unable to carry on to the top, because just above her was a large over-hang, and she would not be able to negotiate it. She was brought down to safety, flushed with joy at having managed to impress upon us the need of including her in going up cliffs as well as down. That evening she was sent to her sleeping bag early, seriously reprimanded. She cried a little until I came and sat beside her and told her a story.

The following day, Noa was one of the climbing team. Three months later, we built a climbing wall in the kibbutz on the side of the granary wall. She was the only kid of her age who got to the top. Of course, real serious climbing up sheer cliff faces neither she nor any of us attempted as none of us had that type of expertise. Noa did not have the strength to be able to carry all the extra equipment needed for such climbs. Several years later when she was in her late teens she did join a climbing club; there she excelled way above many other so-called experienced climbers. Noa just lived for these climbing outings and could often be found in the early evening sprawled out on her bed looking at maps trying to figure out where next would be the best place for a climb. She was by then, quite proficient at reading and understanding maps. Other kids, in the evening would be plonked down in front of the TV or playing or reading books. She spent her spare time poring over maps. She was, by all accounts, a most unusual child.

When she was about twelve-years-old (if I remember correctly) and by then an experienced climber, I was still worried for her safety: Climbing as a sport has a notorious reputation. I tried to think up some other occupation that would give her the thrills she needed and would captivate her like climbing; something she would not have quite so far to fall.

"Why not let her take up horseback riding?" I thought to myself. True, you can fall from a horse, but it is not as far to fall. We have stables on the kibbutz and kids are encouraged to take up the noble sport. Of course, Noa took to riding as if she was born to it. What I didn't know was

that Noa had already started riding lessons without us, her parents' knowledge. Only several months later did she deign to tell us. She seemed at one with the horse; she flowed with it. Although she took her lessons seriously, all she really wanted was to gallop out in the fields as fast as possible. After I first saw her flying past us at breakneck speed, encouraging the horse to go even faster, I took her aside and got her to promise me that from then on she would always go riding with a rider's helmet. She agreed, I am sure just to pacify me, because a week later I saw her streaking across a field like a Valkyrie with beautiful auburn her hair flowing out behind her -- and of course, with no helmet. She did fall a couple of times at the beginning of her riding career, but apart from a few bruises and hurt pride she always came off all right. From then on she was like the wind. Often she could be seen riding bareback almost as if she was an integral part of the horse. There was one horse she had especially grown attached to; the horse's name was Patsy. Everyday before school, Noa went to the stable to feed and say hello to Patsy. After school, if there was not something of world-moving importance, she would be there grooming, talking and sometimes with her horse Patsy, conducting as if she was the audience. Patsy was as fond of Noa as Noa was of her horse. Patsy was never at ease when someone else was sitting astride her.

Noa would often go on short rides alone in the fields around the kibbutz. Sometimes she would go even a bit further abroad. She ignored my warnings, when I said to her that riding alone can be dangerous. It is not that she was being naughty; she couldn't resist the call of the wild. She would just suddenly take a fancy to go off on her horse Patsy. She was incapable of thinking that anything could go wrong to her. She was such a loving child that it was impossible to ground her.

One time there was an incident which we learnt of only after the event. She'd gone out riding on her own, and this time she took along our dog Rocky whom she loved as much as Patsy. They arrived at the furthest point she had planned on going to, a place we called The Horses Pool. It is a fairly large pool of free running water where in olden times travellers used to stop and water their camels, their donkeys or their horses. She allowed Patsy to drink her fill, and when the horse had drunk enough, she draped its reins over a low branch of a nearby tree so that she could be in the shade. Noa

and Rocky sat resting together on a rock overlooking the pool. Suddenly a man approached from out of nowhere and asked Noa if she would come with him. She knew not to take presents from strangers and if possible not to talk to them, but suddenly, here she was on her own, miles from anywhere, and no one to turn to for help. She replied to the stranger that her parents told her not to have anything to do with strangers, and got up to leave. The man grabbed her by her arm and started to drag her towards a thicket. She started screaming, and Rocky who was already growling at the stranger made a flying leap and sank his teeth into the man's arm. The man let go of Noa, and she immediately made her escape. She ran for her horse and made a flying leap from a rock nearby onto her horse, and in a cloud of dust she galloped away from the scene. The man made a futile effort at trying to catch up with her, but it was impossible. Noa looked back to see the man sitting by the pool bathing his wound. Rocky was unharmed and chased after her.

It was early evening, not yet dark. We were sitting outside on our porch when Noa turned up astride the horse. She never brought the horse to the house. She knew it was frowned upon bringing horses within the confines of the kibbutz houses. She jumped off the horse, and crying ran to us. Between sobs she blurted out her story. We were thankful that she had returned unharmed, but we were very agitated by what had happened. I telephoned the police department; they immediately sent a couple of officers around to question her. The police had already been on the alert looking for a very dangerous man who had broken out of a mental institution and was reported to have been seen in our area. The policemen were gentle in their questioning of Noa. After they'd finished, a man hunt was set up in the area she had mentioned. A short time after, the police caught the man in the same area defined by Noa. Noa learnt her lesson from that incident and never again did she go riding or hiking alone.

Although Noa knew how to read music and was using this skill of hers for conducting and reading maps, she rarely read books. Then out of the blue she was bringing home piles of books from the library. She was, I don't know how, reading everything and anything, from westerns to books on astronomy. I am not sure she understood everything she brought home but

she waded through almost everything. We found ourselves suddenly inundated by questions as to why? If the universe is expanding, why it is we can still see all of the galaxies? Or, why is it that animals all have different lengths of time for gestation? She'd discovered the world about her and was awed, intrigued, and full of curiosity. By now she was going to bed later at night, and although she always read a book in bed she still insisted I tell her a story before she fell asleep. Her love for animals was still that of a child, like a child's love for a puppy, but it was obvious that even though she conducted before them or read to them from a book, she was not really reading to them: It was for her own benefit. She was in love with books and most of the time could be found carrying a book under her arm to wherever she was going. Although she could still be seen tearing around at top speed, now it was with a book under her arm, clenched between her teeth, or in a satchel.

In spite of improving her reading skills, Noa was having problems at school. She was failing one test one after another. With a whole year of disappointing results at school, mainly because of her test failure rate, she was falling behind worryingly. Her teacher was no less worried than we were; she knew that Noa had greater potential than that exhibited in her school exams. The teacher asked us if we agreed to have Noa examined by a specialist to see if anything can be done to help. The results, written in full hand by a certain Mrs. Bat Ari, were surprising. They read: Although Noa is a very intelligent and outgoing child and excels in almost everything she puts her head to, she has an unmitigated fear of failing her tests and therefore, before and during any exams she becomes so tense that she is unable to even achieve even minimum results. Mrs. Bat Ari finished off by saying that the situation, especially at Noa's age, is reversible. With her aid and a little patience Noa could be helped over this obstacle to furthering her education. She stipulated that Noa needed several months of special tuition in getting over her fears. Our daughter was fallible after all.

Noa not only took to Mrs. Bat Ari, she looked upon her as her best friend, and improved much quicker than had been forecast. After every meeting with her counsellor she would come home gushing: Mrs. Bat Ari said this, she said that, she showed me pictures of her family and her dogs, etc. Three months later she passed her first school exam. Although, as she told

it, she was tense but not nearly as tense as she used to be. From then on her she improved exponentially. What a child!

She is twelve years old and is going through mood swings. When I asked her mum, she confirmed that Noa was going through her first periods. She had started sprouting small breasts and was beginning to look more and more like a woman than a wild tomboy. Nevertheless, she still liked and craved the great outdoors, climbing, riding and animals; maybe even more intensely, only not so stridently.

For her thirteenth birthday we bought her a camera. It took a little time to get used to the idea of not putting her finger in front of the lens, and not moving whilst filming. Eventually she got the idea and became quite proficient at it. Slowly she began filling the walls of our dwelling with lovely animal and country scenes. At the beginning she took only black and white photos, but after a while she started using colour film as well. She had by now her own special knapsack which always contained her latest book, the camera and sometimes if she remembered she'd add a sandwich. Often she would forget that she needed to eat and was left begging something to eat from other people on the outing.

Noa at the ripe old age of fifteen had joined a book club, and once a week in the evening they would discuss the books they'd read. Noa took an active part in the discussions. How she managed to keep awake until ten-thirty or even eleven, I don't know. She always came back shattered and sometimes fell into bed without even undressing.

She is now sixteen years old and has joined a debating society in her school; she'd been recommended because of her book club discussions. Noa was becoming very vocal and persuasive in these discussions. Of course, in the debating society she was often called upon to persuade people to accept a particular point of view which was in opposition to her own views. After a while, she was become very adept at this form of debate. After only a year at debating she was chosen with four other children to represent their school in a country wide school debating contest. They achieved second place.

Noa
Chapter 11
Supposedly grown up already
From fourteen to the inevitable end

It is hard to recall everything that happened in this period, perhaps because not a whole lot did. Noa stopped growing altogether. Her serious deterioration was, at the beginning, hardly noticeable. Yet, as it progressed, it was possible to see a difference in her almost from one month to the next.

We still did our utmost to make Noa's life as liveable and enjoyable as possible. We still took her out in her stroller, talked to her and played music especially for her. She continued to enjoy these things, but slowly and surely to a lesser and lesser degree. There was nothing we could do to stop her deterioration, much as we would have liked to.

She lost her plumpness and was becoming more spastic and increasingly apathetic. Noa also lost her ability to laugh out loud. Was it because of her apathy or something simply physical? I do not know.

I was dreaming more and more often at night and having day dreams of her getting well and turning out to be the girl we could only have wished for. Sometimes I felt that this dreaming of mine was quite real, almost as if by wishing it, it would become true. But, of course, to no avail.

Although she was losing weight, lifting her everyday had become more and more of a burden for us: We weren't young any more; we were both in our mid forties and each of us had our back problems.

Noa had long ago become part of the human scene in our community with her mother, Sarah or me pushing her around in her stroller. Still, for us, it was becoming not only more difficult physically but also mentally. We hardly ever left the kibbutz to go out and enjoy ourselves, to travel abroad, to visit family. We were continually involved with looking out for Noa's continued comfort and health, and instructions for whoever would be looking after her in our absence. Just the logistics of it were tiring.

This is unbelievable, and I still find it incredible: At the age of seventeen, like all other Israeli youth, Noa got her call-up papers. We had to go and explain the army bureaucracy why Noa will not be able to take an active part in defending our country. It is a classical case of one hand not knowing what the other hand is doing.

Every year a person would come from the National Insurance Company to see and confirm that Noa is eligible for the pittance that she was allowed. They always came asking the same questions. They'd look at her so as to confirm that what they were being told was true and when satisfied they'd spend half an hour filling out a report. Every year it was the same thing over again. Someone comes and asks us the same questions: Can she walk? Can she eat? Is there anything she can do? During one of these visits I asked the lady filling out her questionnaire, "Tell me, is all this absolutely necessary?"

They always left with the same answers.

"You guys out there by now surely know everything there is to know about Noa. Isn't that enough? Isn't it already recorded that she has a one hundred percent disability?"

The answer I got back was yes, it is recorded, but they have to make sure that she is still alive and that you are in need of the monetary help. It was explained to us that many people out abuse the system, for instance by putting on false plaster casts, sitting in wheel chairs until the check has passed on. These people are severely punished if and when caught out.

Noa was, if I remember correctly, eighteen-years-old -- very thin and almost completely apathetic -- when one of us brought up the subject of placing her in a nursing home. It was not at all easy suggesting it, even just between us. All of her life we had been against the idea. All of her unexpected and extended life I had wondered to myself: How can people desert a child after it was born to them? Just because it had some malformation or some life-threatening disease! All of a sudden we were discussing this same dilemma eighteen years later. It was not easy; it was a combination of things that brought us -- how shall I say it -- to our knees.

We shopped around in our vicinity and eventually found a place that was the embodiment of loving care for children with problems similar to hers. The place is called "The Sacred Heart"; it is still there. It is a monastery run by Roman Catholic nuns in downtown Haifa. Much of the area is to this day quite run down, but long before Jews became the majority in Israel it had been built and occupied by German Templars. The monastery Noa was about to move into was a hundred-year-old building complex built around a large central square. There are three stories to the buildings encompassing the square. Although the nursing home was run by the Catholic Church, it was not wealthy. All the same, it was well supplied by nursing staff and volunteers who came over regularly from Europe to help out. There was a sense of holiness in the place. No one was rejected because of race or religion.

Noa finally moved in it and became obvious to us that we were not alone; there were many other children with diseases similar to Noa's. It was explained to us, when she was finally accepted into the home, that they usually don't accept children above the ages of eighteen or twenty, but because she was so small and child-like they allowed her to stay.

There was a very small contingent of nuns -- four, I think. We never saw more than one or two at any one time, but there was a large nursing staff twenty-four hours a day. They treated and cared for all the patients with the same amount of love and care. It was uncanny, the number of loving and caring people all working in one place.

Not all the children placed in the home had relations who came to visit them on a regular basis. We made it our top priority to do just that. The home had all manner of activities for the children, although it seemed to us that many of the poor individuals living there hardly knew what was being done for them. Many of them were in a state similar to Noa's, unable to express joy or understanding. All the same, the staff treated every one of their charges as if behind the most apathetic face there was someone appreciating and enjoying their efforts.

In the nursing home there were several rooms where the children were helped through different activities. In one room there was a swing built especially for children with disabilities such as Noa's. There were also building blocks and all manner of things that were there to stimulate the child's almost and often dormant senses. Later on, another room was added with a water bed and all manner of lights and shapes that moved and flickered around the room. In a corner of the room, there was a transparent four- or five-inch-diameter pole containing a fluid with bubbles continually rising through it. The children would place their hands on it and feel or sense the bubbling of the water. This room was really did provoke and wake up the patients' often dormant senses. There was also a computer room.

I was told by a male nurse who took Noa into the computer room, that they had a program which enabled the patient to see shapes and colours on the screen. By its use he was able to form some sort of dialog with Noa. At first we found it impossible to believe. Can you imagine, after all those years when the only dialog we had with her was completely one-sided, and here was a person telling us that it was possible to get through to her, somehow! I was shocked by it. How could it possibly be?

The whole complex of the building was in the form of an upside down horse shoe with the lower part enclosing the rest within a high wall. As I've already mentioned, the whole surrounding area was run down, and rather seedy part of town. Parts of it were like many port cities, run by the most unholiest of denizens. One day we came for a visit, and just as we passed through the gate my wife saw a suspicious object backed against the wall of the Monastery. It was a black suitcase. Just a few days earlier it had been mentioned in the newspapers that someone hurled a grenade at someone else in this same vicinity; there were some really nice characters in this area. We entered the home and immediately alerted the nurses and the nuns about the suspicious object and the probability of impending danger. The police were informed, and immediately the whole road (it was a cul-de-sac) was closed off. A policeman nonchalantly sauntered down the road, grabbed hold of the suspicious object, shook it, and whilst walking back to the police car nonchalantly tossed it into a nearby dumpster. He didn't seem the least bit perturbed by it.

We visited Noa every week, and were on good terms with all of the nursing staff. We also got to know some of the children and took part in their celebrations. There was one really big celebration: It was the nursing home's hundredth year. A big celebration was held for the staff, the children and their parents. Also present were dignified guests from around the country and abroad.

Noa was wasting away; it was obvious to us that she could not last long. A year after we had brought Noa to the "Holy Heart" I went to South Africa alone to visit my much older daughter, leaving my wife behind to carry on with the visits to Noa. I'd been there only four days when I received a phone call from my wife telling me that Noa had passed away . . . Noa was no more. I immediately booked a flight back to Israel and arrived in time for the funeral. My wife told me that she had been urged to come at once to the nursing home because Noa was dying. By the time she arrived, Noa was

pronounced dead. All that was left for my wife to do was to close our beloved daughter's eyes.

Noa had had a prolonged and sad life, but maybe for her it was not always so; we will never know. But without a single doubt she gave us a lot. She showed us that love and compassion can and should be showered on everybody. Noa with her smile and laughter was a light for us during those sad days. It was such a shame that she was not able to experience if only a little bit more of life; she certainly deserved more.

Now Noa is a loved memory and a stone in a corner of the kibbutz grave yard.
May she rest in Peace.

Noa Chapter Twelve

Shall I carry on with the other Noa? What's the point in it? She died, didn't she? True, she died, but for me there had always been the other Noa, the healthy, wild and beautiful Noa that I could only have wished for. In many ways for me she did live. She lived on in my dreams, my day dreams, and my imagination and in my wish fullness. Therefore I will carry on with my dream Noa as she would have been up until this day.

Boy, was she becoming beautiful! Suddenly, there were boys coming round to visit her, as if they were crawling out of the wood, only now not to build something with mud and planks or to play at marbles. They came courting, panting after her like after a bitch in heat. At first, she loved the attention she was getting from all those boys. She even started dating a few of them. In the beginning it was hard for her to differentiate between suitors who were truly interested in her friendship and those who were only interested in getting into bed with her the same day. One day, she told her mother of a young man who she thought was really interested in her for all the right reasons, and then how he tried to force himself upon her. She refused to give his name. She said she was definitely interested in the opposite sex but was not willing to give up her virginity for any panting sex maniac, certainly not yet. That is how her mother said she phrased it; her attitude as far as we were concerned, was certainly all right.

The young man who had tried to force himself upon her did not turn up for school the next day. He was suffering from severe stomach pains, and

for several days took no part in school games or athletics; she'd taught him a lesson he wouldn't forget for a long time. After that, her suitors dropped off in drastically, though not completely. When we would ask her what's wrong with so and so, she'd nearly always have something derogatory to say of him: This one is a meat head; all he thinks of is how he looks, "Do you know mum he goes around all the time with a comb in his shirt pocket?" This one has nothing at all between his ears; he's just a lump of muscle-bound meat, and so on and so on. Noa was one of the queens of the class, but many of the boys and girls in her class called her the "ice queen." It didn't bother her, though. She was far more advanced than most of her classmates, mentally, physically, and was almost certainly more intelligent and mature. Noa had no time for boasting about her capabilities; she had no time for beautifying herself. She was Noa net. What you saw is what you got.

She was seventeen now, and all this time she craved for real friendship -- a true male friend. One day, at the beginning of the new school term, she found him. His name was Daniel. He lived in the nearby town, and because he and his parents preferred a kibbutz type of education he turned up sitting next to Noa. Daniel was a brilliant kid, just the sort who provoked the kind of mental challenges that were for her the essence of living. He was handsome, witty and strong. But there was a problem: He was in a wheel chair.

Only years later would Noa admit that she had fallen in love with Daniel the very first day he sat next to her in class. As their friendship grew, so did her love for him, in the course of time, loving him to distraction.

He nearly always sat next to her in class, and from day one they could be seen together all the time. A few weeks later after having met Daniel, she passed her driving test. From then on almost everyday she would travel to visit him at his house, or she would bring him to visit in the kibbutz. By now, Noa was allowed a room of her own away from her parent's house.

Daniel was independent and refused help, unless it was absolutely necessary. He was a strong kid. Like Noa he had been born on a kibbutz, therefore kibbutz was not strange to him. His previous kibbutz was on the northern border.

One day, when Daniel was twelve years old, the kibbutz was bombarded suddenly by a barrage of rockets. At that time, Daniel with a whole bunch of other children had been playing outside his parents' house. Daniel was the only one who was hit. He suffered from a piece of shrapnel slicing his spinal cord and was left permanently crippled from the waist down. After his recuperation, his parents decided they had had enough of pioneering and went to live in town. Daniel had been living in town ever since. But he was unhappy with town life and continuously nagged his parents until they relented and enabled him to change schools. That is how he came to sit beside Noa in the kibbutz school.

When Noa went to visit Daniel in his home in town, his parents were delighted that Daniel had found a young woman friend who was so intelligent, friendly and beautiful. They accepted her into their household as another of their children, as the daughter they'd never had.

Noa took Daniel on all her field trips wherever they went; he insisted on going, possibly because he couldn't bear to be apart from her. One day, after having returned from a field trip, she told us that Daniel had insisted on doing some rappelling. With the help of the whole troupe he succeeded! She explained in great detail how, with the aid of the whole group, they found a suitable cliff; how they tied him into a harness; how with the aid of his exceptionally strong arms he lowered himself down; how, when at the bottom, he said that it had been the most exciting thing he'd ever done in his whole life. And he insisted when at the bottom, "I want to do it again." He did do it again, another three times. He'd had the day of his life, he said, and all thanks to Noa.

A couple of days later Daniel was visiting Noa in our house. Noa went into the kitchen to prepare tea and biscuits. Whilst she was puttering around out there, he said to us with a quiet confidence, "I am going to marry Noa one day. Only when she is ready though, I'll not push her. I know she loves me, and as for me, she is like a part of me. I love her beyond belief."

Just then Noa came back with the tray loaded with drinks, and she asked, blushing: "Have you been talking about me?" It was passed over by Daniel asking her when she was due to be called up for the army.

"I've got my papers for the autumn call-up. I don't remember when exactly. Why do you want to know, Daniel?"

"Why? Because I'm also going to join up!"

Without mentioning his disability, Noa queried: "Are you sure they'll let you?"

"I know of other kids like me, and they managed to join up. You just need to nag them enough and prove to them how vital your skills can be for the army. There is a good chance of my being accepted, I know for sure that I could do well in computers."

Everyone who saw them together accepted it as a fact that that was the way it had to be; together they were like one. They could often be found laughing together over some private joke. They'd go swimming together and to the films together; they were always together, and although they argued occasionally, it always ended peacefully.

September the fourteenth was her call-up day. We all accompanied her, us and Daniel and his parents to the assembly base. I'd never seen so many young women before; Noa was one amongst hundreds. We were very proud of her when she came back home after completing her basic training, wearing her newly pressed army uniform. She looked so different, so grown up and so lovely.

Noa had been in the army for a year when Daniel was at long last accepted into the army; it hadn't been easy at all. He'd sent letters to everyone and anyone who he thought might be able to pull the right strings and assure his recruitment. He was, if at all possible, even more proud of his uniform than Noa was of her uniform.

Noa was in a very special unit whose job it was to scan a length of border some twenty kilometres long, twenty-four hours a day. They used powerful binoculars capable of seeing at night and through fog. Connected to monitors, they had the job of reporting incursions, or on anyone approaching the border. They maintained constant contact with the local infantry units scattered along the border, looking out for Hamas militants or terrorists attempting to infiltrate into Israel from across the border.

After a year on the job, Noa volunteered for an officers course, which meant she'd have to sign on for another two years. She passed the officers course with flying colours and was eventually in charge of two border observation posts. Whenever Noa had time off, or any spare time at all, she

would go visit Daniel in his camp. He worked on something to do with computers, something top secret. She was becoming a regular visitor to his camp. They weren't more than fifty kilometres apart at any one time, so it was easy for them to visit one another. Both were enjoying life thoroughly, and by now they made no effort to hide the love they felt for one another. Of late, as Daniel filled her every wish for happiness, Noa was coming home less. Their visits home became less and less, because their army bases were closer to the big cities of Tel-Aviv and Jerusalem than to the kibbutz. Therefore they spent a lot of their precious time enjoying life in the city. Their lives were filled to overflowing.

They'd worked it out that they would marry when they finished the army. They reckoned on being discharged at about the same time; afterwards the world would be their oyster. It was obvious to everyone, that that was how it would be.

The tragic event related below is something that has happened -- and continues to happen -- to many Israelis in all parts of the country. It is a part of their unfortunate fate or destiny, being stuck here in the Middle East; a thorn in the side of fundamentalistic Islam. There are many in this country who have fallen afoul of terrible circumstances similar to this:

They were both three months away from their release from the Army. They met in a Tel Aviv restaurant with a whole bunch of their army friends. It was midday. Spring was in the air. A couple of tables had been brought together to enable the whole group to sit together at one table outside on the sidewalk -- a very popular arrangement in Israel. They were making a lot of noise laughing and joking. Daniel had an extraordinarily good and macabre sense of humour, and he was telling everyone another of his jokes. They had barely recovered laughing from the previous one when Noa noticed a person riding on a scooter around the round-about, then he was heading directly at them. She thought to herself, "If he's not careful, he is going to drive straight into us."

It was too late: He was coming directly towards them. In a flash Noa saw the bulging knapsack on his back and an expression of madness in his eyes. She called out, "Suicide bomber everybody dow . . . n." But it was too

late. He exploded his knapsack just as he ploughed into them. Noa had just started to dive across the table to try to cover Daniel with her body, but she was caught by the blast in mid-air and thrown backwards some eight meters. Noa awoke after only a few seconds. Every part of her body hurt; blood was running from her nose and head. Slowly she sat up and felt herself all over. Although she couldn't hear a thing except for an insistent buzzing in her head, she was all right. She suddenly scrambled up, stepping over people lying on the pavement, not knowing if they were alive or dead She had only one thought in her head: Daniel, I must find Daniel!

She found Daniel: He'd been thrown in her direction and had lain almost right next to her. He was alive, but barely. Although Noa saw no blood, she knew that he was mortally wounded. She cradled his head in her lap and cried: "Daniel! Wake up, please wake up, Daniel! Don't die Daniel. Please don't die! We have so much to live for." Daniel opened his eyes and looked up into her face. She could see that her Daniel was beyond help. He wasn't able to talk, but she managed to read his lips as he spelt out "Noa, I love you." With tears running down her face Noa spoke to him again:

"Daniel, please don't die, you can't die. I'm pregnant with our baby. Who will play with him? Who will tell him stories? Who will love him like you? Daniel I love you so much, please, you can't die, not now."

Alas, it was too late. One moment he was staring up into her eyes, and the next his eyes closed and he was no more.

There was a lot of noise, ambulances, police car sirens, cops, passers by, and people that had already been in the area; all shouting, calling for a medic or help and the sounds of the wounded and dying. A cacophony of noise. Suddenly, a new sound spilt the air making all the other noises sound as if nothing; D A N I E L. Noa screamed and screamed until the air was expended from her lungs; she then collapsed upon her loved one. That was the last Noa saw of Daniel.

She woke up later in hospital with a large bandage swathed about her head.

We rushed to the hospital as fast as possible; both of us, her parents, and Daniel's parents. It is a two hour journey for us to Tel Aviv. We made in an hour and fifteen minutes. Daniel's parents were not told about his death until they arrived at the hospital. The hospital was like a scene from hell:

parents, loved ones, friends, people crying, screaming, people in shock standing around shaking, and amongst all these were Daniel's parents. It would be fair to say that we were also in shock, but we were also relieved that our Noa was alive and had suffered only minor wounds.

After a couple of days Noa came back to the kibbutz to convalesce. Apart from attending Daniel's funeral she didn't go out at all. At the funeral Noa stood by the new grave, immobile and in complete shock. People came up to murmur their condolences and shake her hand or hug her. She just wasn't there. She didn't respond. She was as if dead.

In our house, Noa now stayed in her old room. Apart from going to the toilet, she remained in the room with the curtains drawn, not talking, barely eating. We brought her food, undressed her for bed in the evenings, and in the mornings woke her and dressed her. She slept much of the time, and when awake she was as if sleep walking.

A psychologist came to see if she could help Noa. She advised us not to try to talk to her about what she was going through. "She is a healthy young woman, and she will heal, she will come out of it on her own."

Noa was in a state of shock, but after some seventeen days she started to speak. In the beginning, she would only say she was or wasn't hungry, but eventually she emerged from her room and took her meals with us. It was hard to stoke up a proper conversation with her, but after a month and a half she announced, out of the blue, that she was pregnant with Daniel's child. From then on she was back to speaking, but all the happiness, all the liveliness, the spark that was Noa seemed to have gone up with the explosion. Although she would speak when spoken to, and even occasionally start up a conversation, it was as if she was dead to all feeling and emotion.

Friends came to visit her. When, with good intentions, they told her a joke she would obligingly smile, but humour had gone the same way as the spark of liveliness.

One day, about four months later, we had a visit from a young man dressed in the uniform of a captain; he was as red headed as a red-head could possibly be. He introduced himself as Red Bar-On and asked to see Noa. She was taking a nap, and I asked him what he wanted of Noa. I told him that she had of late gone through a terrible trauma and wasn't yet up to

talking to strangers. Red explained that he had been Daniel's superior officer when he'd been killed, and that he had been sent abroad almost immediately after that happened. Only now had he plucked up the courage to come and visit Noa. He'd heard that she had gone through a terrible shock, and he had not wanted to disturb her, until now. He said that now that he was here he would be willing to wait until she awoke.

We sat for about half an hour talking -- mainly about Noa and her relationship with Daniel. We also told him about Noa, that before her recruitment into the army she was very much a tomboy. Now the tragedy had robbed her of all that was dear and important to her. We told him that now; all she was capable of was just getting through the day.

Suddenly Noa appeared in the doorway. She was wearing her very first genuine smile.

"Hello, Red. I'm so glad you took the time off to visit."

His face lit up also, in a shy smile. "Good to see you, Noa. Please accept my apologies for not turning up earlier."

They sat for a while talking about Daniel, and Red told us how important Daniel had been to their unit, and that his loss was the army's loss. We served them coffee and fruit. As Red was evidently hungry, we made him a sandwich, which he devoured as if he hadn't eaten in a long while. We found out later from Noa that Red was an orphan and lived on his own. He had no family at all that he knew of. Noa also told us that he had quite simply by ambition and willpower -- whilst in the orphanage and later as an adopted child -- learnt and brought himself up to a level of studies that many more fortunate children often found it impossible to reach. Called up for army service, he was soon recognised as a genius in computer sciences. Later on, he achieved officer status in a very secretive and highly rated unit. He had done all of this all on his own, and was considered by many in the army as the stuff high officers were made of. It was hoped he would stay on and make the army his career.

To our surprise, Noa invited Red to walk with her around the kibbutz. She hadn't been outside of the house since Daniel's funeral.

They arrived back at the house some two hours later, talking their heads off. Noa was even occasionally laughing. Was she at last on the mend?

Although Red's army base was a hundred and fifty kilometres away, he came to visit her on weekends whenever he possibly could. He would even get away sometimes in the middle of the week. It was becoming obvious that he was in love with Noa, in spite of the fact that she was pregnant with Daniel's baby and starting to show it. Noa didn't talk about her feelings for Red but clearly she enjoyed his company to the exclusion of everyone else.

The day she had been waiting for ever since Daniel's death, the day she was to give birth to their child arrived in due time. All along, Noa had refused to undergo ultra-sound; she didn't want to know in advance the sex of the baby. For her it was enough to know the baby was a part of Daniel. She was rushed to hospital in the middle of the night when the time between her birthing pains became short. The baby was born a healthy four and a half kilo boy. He was born three and a half hours after Noa had been admitted into the hospital.

We had telephoned Red to tell him that Noa was in hospital and about to give birth, and he succeeded in getting to the hospital in record time. He arrived just as Noa was handed her baby boy. Noa was overwhelmed with joy when she saw the baby, and even more so when suddenly Red appeared next to her, almost as if he was the father of her child.

Three days later, Noa came back to the kibbutz. She was given a small apartment of her own in which to start up her own little family unit. Red came to visit Noa and her baby almost every day. The day of the Brit (circumcision) was the gladdest and the saddest day Noa had experienced since Daniel's untimely death. She almost broke down when after the Brit she announced to all her family, friends and neighbours that from this day on her baby boy would be called Daniel. Had Red not been there to hold and hug her she would have broken down in grief, but Red was her rock, something to cling to.

After four months, Red moved in to live with Noa and Daniel. On Daniel's first birthday, Noa and Red married. It was the happiest marriage the kibbutz had experienced in many a year. There was hardly a dry eye to be seen when Red put the ring on Noa's finger and declared in a loud and resonant voice his wedding vows. Noa looked absolutely radiant, she was so beautiful. The smile on her face on that happy day was the radiant smile I

remembered several years earlier when she went gliding down the cliff face for the very first time.

Noa and Red didn't stay on long in the kibbutz. He'd risen to the rank of major and was given a family house in an army housing unit on the base. Now it was up to us to visit them. On our frequent visits to Noa, Red and baby Daniel, we also brought little Daniel's grandparents along with us. They had gotten to know Red and looked upon him as their son.

Noa resumed her adrenalin activities and encouraged our grandchildren to take part in them as well. We were even more worried that they, our grandchildren, should take part in such activities than when Noa herself did.

The years went by. Red made the army his profession in spite of very lucrative offers from industry in civilian life. His response to people trying to recruit him was, "I have been recruited once and that is enough."

My sad and happy tale ends here, where a happy ending should end. We are grandparents of five grandchildren, four of them from the loins of Noa and Red.

If only ... it could have been true.

Then maybe it was!

This below is the Canavan Foundation's address, we were in contact with these people, especially during Noa's life, and we still are.

Canavan Foundation International. Founded 1992. Provides information and education for persons affected by Canavan. Offers literature, phone support, conferences and advocacy. Supports research. Online support available.

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