Bells for Laughter

What do you do when hope is taken from you?
You make your own.

Margaret Holmes

1983.

I WAS DRYING the last of the breakfast dishes, on that day in February, a pot of marmalade simmered on the stove and a Haydn cello concerto spun on the record player.

> The phone rang.
> And the world shattered.

Our grandson, aged just one year and a day, was in the Intensive Care Unit with extensive head injuries. I rang my husband and somehow remembered to turn off the element, and lift the stylus from the record ...

Small, so very very small. Tubes everywhere, machines — but bleeping steadily and reassuringly. Eyes closed he was perfect, but his little head was swathed in bandages held on by a stretch cap. Bed propped up so he was almost upright. Ventilator, catheter, tubes for nourishment and medication, heart and respiration monitors — all on one twenty pound body.

We sat by the bed and willed him silently to hold on, and I remember how the tears just wet our faces. Then we were told that he was not expected to live, that if by some miracle he did he would be hopelessly braindamaged.

On arrival at the hospital, we were told he had needed emergency surgery to release a large subdural haematoma and received transfusions. Twentyfour hours later he required a further operation, he had already had a large area of shattered bone removed and was to require a further burr hole on the other side of his head.

We listened — I think we took it in, but we were numb, and it occurs to me now, very very polite as we said that we wanted him, regardless of his condition — physical or mental — he was not to go into an institution.

They pointed out that he would be severely multihandicapped, but we insisted that his place was with us.

We went home. I made the marmalade and finished the housework, hanging out washing in a day that mocked me with its blue and gold perfection. And we wondered how and what to tell the children — for there were criminal charges to be laid.

I took the Haydn concerto from the turntable to put it away and stood for long minutes with it in my hand. Richard had loved that record, he slept in his pram in the lounge and there had always been music, the Haydn especially almost seeming magical. He would stop crying after the first few bars when the slow reassuring voice of the cello entered, and had generally fallen asleep by the end of the first cadenza. I had only the day before chanced to read a Reader's Digest article about the

Autistic Savant boy Leslie, and as I held that record I vowed that I would take that recording to the hospital, that music would be the means to Richard's recovery, and that we would never give up hope.

We did give up hope, many times. Times that we prayed for him to die, afraid that his superb physique would keep him alive, with a useless brain, times when we shook our fists at God. (Not why us, never that, why a little child ?) Then we prayed just as hard that he might live, going to sleep calm in the acceptance that he was in God's hands — and waking in the middle of the night, in terror and grief.

Then there was the cruel week when our daughter refused us the right to enquire after him — she was only seventeen, and under very great influence — and so we didn't know if the child lived or died.

News came through again after a change of heart and lo, he was still battling. The nursing staff gradually brought him out of the coma, which had been induced in order to rest his brain as much as possible and he was taken off the ventilator.

I have had some dealings with children with both brain damage and cerebral palsy, but I could not remember ever having seen anyone as bad as Richard.

One eye turned inwards, the other stared mindlessly upwards and his mouth lolled open, tongue protruding. He was an empty shell yet he trembled violently from head to foot. The injury was on the right and so he was paralysed on the left, at the same time the right arm and leg jerked continuously. I took him in my arms and it was like holding a sparrow which had beaten in fright against a window.

Three weeks earlier Richard had been walking around furniture, laughing, and speaking a handful of words. He had been the 'smilingest' boy and now he was totally unresponsive — worse than newborn for he could not even suck although he could swallow a little food placed directly on his tongue. He could not hold up his head — one day he would sag in a little wheelchair and be unable to close his mouth to retain the food, the next day he would be curved backward and rigid so we could only slide custard between his teeth with a wooden spatula.

Before therapists had warned not to give him anything to hold someone had given him a rattle, I don't think I will ever forget the sound of the rattle shaking in time to his tremors.

He was transferred to the childrens' ward and I asked permission to use a cassette player. I was frightened at first to turn it on, but my husband and I each held one of Richard's hands and I put on a tape of the Haydn cello concerto. Did we imagine that he wasn't trembling so much, that he was sleeping more restfully?

> For the next four and a half months, I gave him four or five hours of music a day.

We were told to stimulate him but I thought it more important to calm him, in an atmosphere untouched by violence and terror.

From the time he was born Richard and I had our special times — Nana and Richard listening to music. We used to feel the pulse, or beat out the time, or just sit. I was going to relive those times, for hours at a stretch if I could.

As we had surrounded him with love in the ICU now I sat and loved him while music filled the little world of his cot and my chair. To the Haydn was added Bellini and Vivaldi oboe concertos and Mozart clarinet music as woodwind music is especially calming. Some of the Mozart trio and quintet he had actually heard me playing 'live' and I hoped he might remember.

I gradually added more stimulating music. Mozart ballet music was perfect for its contrasting sections as was the Bach B minor suite which had also been one of Richard's favourites. It was heartbreaking to hold that shadow child and remember him sitting in the middle of the floor — four square on his diapered bottom — jiggling in time to the Bouree or rolling over chuckling at his own efforts at keeping up with the Bandinerie.

Mozart piano music, Haydn symphonies, Telemann trios, Leopold Mozart's Sleighride and Toy Symphony ... the terrible cerebral scream was changing to a healthy bellow. He held his head up and he smiled, that gorgeous total—body squirmed smile of a six weeks infant — bitter sweet in a child of fourteen months.

I was never sure if the sobbed chuckle he gave when I picked him up was because he remembered me or whether I had become familiar, but there was little doubt that he remembered my younger children then aged 7, 9 and 13. He was more relaxed with them and sometimes the fisted left hand would uncurl just a little.

Two months after the injury he laughed when a red pompom tossed between two therapists accidently hit him on the chest, fluid, which had caused his head to swell, was now equalised spontaneously, and we were told he would probably not require a shunt.

Three months after he showed recognition of a piano keyboard on TV, a month later he grew excited over close—ups of violin and clarinets. Although he could not focus for long he watched a changing pastel pattern to Bach's Air on a G String, an advertisement for coffee, I think, music he would not have heard for four or more months.

> We were allowed to take him home.

Once before, he had gone away from us for a week, and had been beside himself with delight on his return. That time he had held out his arms to first one of us and then another, and had crawled from room to room visiting old treasures. This time he was bewildered as if catching a little of our joy but when he was shown the piano as part of his triumphal tour he gave his sobbed chuckle of recognition.

I bathed him. I had last given him a bath the night he left us, a week before his first birthday — then we had splashed water at each other and laughed, and he had wrinkled his nose with water drops on it.

Now I held a new—born baby and I cried. The little things.

December 1983.

He has been home now for six months. he still cannot sit alone except in an inflatable dinghy I use to bath him in, inside the big bath. Fluorescent and wildly patterned, it looks odd hanging on the bathroom door but makes it much easier to support and wash him. he can, however, now roll over dragging his left arm free. For weeks I thought that my whole life was going to be a child pitifully crying on the floor but once he learns to roll the crying stops, and lately he has begun to caterpillar across the floor, pushing with his right foot and 'winching' with his right elbow.

His eyes now focus reasonably well unless he is tired or in the presence of an unknown man. He can see only to the right but has found that he can look at a book placed sideways on the tray of his special highchair.

We have put a leather bracelet with small bells laced onto it round his left wrist and as a result, he is far more aware of his left hand than most left hemi's even though he picks his hand up and shakes it rather than moving the hand. His laugh and the tinkling of little bells are his signature tune.

A recent CAT scan shows there is gross right cerebral hemi atrophy but we are hoping to educate the left side of his brain to take over. he has the physical capacity of a five—seven month child and a mental age officially of ten—twelve months, yet he has an advanced sense of humour, and he knows within a few bars if I add a new recording to my large collection.

Life to Richard — and so to us — is exciting and tremendous fun. Imagine the sheer exhilaration of trying to teach a toddler to feed himself when every time a spoon is placed in his hand he roars with laughter, of grating a carrot to delighted giggles (he cannot see me from the other room but the sound is obviously hilarious), or of bending down to retrieve a toy and seeing a piquant little face laughing at you through the bars of the cot.

For a long time he smiled with one side of his face only, but now each smile is fresh delight — his eyes dance, one side of his mouth quirks, and then the other side lifts. He has a face like a flower, the beauty seen sometimes in autistic children, you find you are drawn to cup it in your hands. With his chin resting dreamily in his hand he looks a Gainsborough child — in apple—green terry pyjamas instead of crimson velvet.

He captivates everyone, everybody almost without exception reaches out to touch him. Not for him the averted eyes or the staring curiosity, and a teenager said just the other day,

> "he is the hub of your house, he just sits in his chair and shines."

And it is true

December 1985.

At three he gets first onto his knees and then drops into a sitting position between his feet. We are thrilled but the therapist says the position is bad as it places too much stress on hip muscles. However we all agree the increased mobility is important and so largely close our eyes to 'W' sitting. he learns to scoot round the floor like this, generally faster than I can walk although he still cannot sit alone otherwise.

1985 - 1986.

In the period between three years and five we walk the dreadful tightrope between epilepsy and toxic intoxication, a time when between the ten or so fits a day he sits or crouches withdrawn and unresponsive in a corner or under the table. We try a new medication, never get the dosage stronger than minimum and then when the fits are controlled take him right off it. No more fits.

He makes another spurt — we find he can sit up, is pulling himself up against the furniture, using one hand and incredible strength as his legs are little help. Has learnt how to tip himself out of the cot, and then how to get out of bed in a frog plaster from armpit to knee. To slam on the brakes of the wheelchair so I go head over heels breaking my wrist, and to tunelessly chant the rhythm of music he hears; to wind up his music boxes — holding the string in his teeth and pulling the musicbox, and to know unerringly which of the three tunes has run down.

December 1987.

Between five and six he learns to cruise up and down the hall with one hand resting on the wall, to run round the table holding on with the right hand in a clockwise direction. Anti—clockwise is slower and requires ever so many tiny little steps. he learns to count by rote with minimal prompting to twentyfour, to sing most of the alphabet, to memorise repetitive stories, to totter holding an adult hand ...

And to sing in tune.

At seven and a half he can walk alone about the room, taking occasional quick steps to stay upright although he must still crawl to support if he falls which he does often. Outside in the playground he wears a skid—lid.

He has an excellent grasp of how things work, is talking reasonably well at about a three year old level although he understands everything said to him.

He has graduated through CCS kindy and IHC pre—school to IHC Special school. And he sings, nearly all the time.

Nursery rhymes, music he has heard my son practice on the violin: Rosamunda and Wild Rose by Schubert, Beethoven's Minuet in G, Tchaikovsky's Chanson Triste, and parts of a Telemann viola concert, these he sings as he plays.

With radio and cassette player he sings great chunks:

of Mozart, Haydn, Bach, Vivaldi, Weber and Hummel. He loves choral music and knows three versions of the Kyria in Mozart settings, loves the Allegri Misereri — and I have heard him trying to sing part.

He plays with music — setting sentences to nursery rhymes or his own little melodies. We get such gems as 'Ricky's thirsty.. fetch the engines.. pour on water' etc, or as an example of his wit and love of words "oh dear, wet can the nappies be."

We sing conversations and his answering phrases seem to me to be sound, he repeats sounds heard incidentally — car horns, sirens, and once to the consternation of the librarian the peeping of the computer. He resets nursery rhymes to other tunes adapting words to fit — twinkle twinkle always has an extra note or two but he is actually singing the theme of the Mozart Maman Variation. he provides final cadences for music heard on the radio, music which I doubt he has heard before as I haven't.

At eight he is tall, a little gangling now and with three adult teeth in the bottom jaw although the top teeth are still baby ones, worn amusingly down by his habit clamping things in his jaws by way of an extra hand. He is talking well although pronunciation needs refinement, and although his concentration is still short lasted he works well with the teacher and is at last beginning to play independently.

He walks fairly steadily and even runs — arms windmilling furiously. Given a head start on sports day, he complains tearfully "Everybody chased me."

And still he sings, even when unwell. The speed in which he learns words and music is astounding. We took him to the orchestra — he sang quietly through every item, so in tune that only immediate neighbours were aware and gave a beautiful clear A for the oboe every single time they tuned!

December 1990.

He has graduated from the Maxi Taxi to the school bus, there is much interest and encouragement as he clambers in and out — plenty of 'big brothers and sisters' to assist him with such love. One day they all call out that he has won an award — and he has, a Mobil Fun Run award, to gain which he has had to run twice round Central school playing field. And he had not fallen over once! I cried, rang my mother who cries too, I find out later that so had the staff, watching that gallant little figure, staggering so cheerfully round the field. He also wins an award for the Special Olympics art with a 'painting' of Cornwall Park.

There seem a large number of end—of—the—year parties, at the RNZFB party he sings "Away in a Manger" solo with the piano accordion and earns a big round of applause.

He talks so well now. “Nanna, I am speaking to you, please listen”

“Rowan, while you are out there ...” And a peacock is a “sort of a bird with eyes in its skirt”.

1993.

Richard will soon be eleven. Although the growth is not as dramatic as between five and eight, he can now hold an excellent conversation, runs very fast, crablike, can read 30 words with a little Makaton help on some, can select colours but not always name them, add a little, recite some poetry and most of his storybooks.

He is still totally incontinent, but can remove shoes and socks, clean his teeth, wash most of himself, feed himself, and help dry the dishes. This he does by either holding the plate under his chin to dry it, or spreading the towel on the bench, wrapping the cutlery, and patting it dry.

He has been to Disneyland with Air NZ (1991) and to several CCS camps. He also sings — most of the time, mainly hymns and choruses, for the music we gave him has been returned to God for His glory. He is a bright and glowing Christian, touching many lives both at our own church and elsewhere, he prays regularly, often stopping his game to request we pray with him.

His latest prayer is that God may heal his left hand.

We know now “Why a little child...”

For seldom has so much love been packed in one beloved parcel.

> ‘Flute for music, bells for laughter;
> Best of comrades, now and after.
> Trust them well—they bear a charm,
> Safe to keep you from all harm.’
>
> — from ‘The Magic Flute’

Epilogue

> The following reflections were added by family more than four decades after the original article was written.

Richard is now forty-four. The child doctors believed would never live, never walk, never speak, and would likely spend his life heavily medicated and institutionalised, has instead lived a life overflowing with joy, music, faith, friendship, and love.

He still sings constantly—sometimes hymns, sometimes great stretches of talking books, sometimes Haydn or Mozart or scraps of jazz. Music still calms him. Worship music especially settles something deep within him after difficult days, just as it did when he was a child lying in a hospital bed surrounded by machines.

He divides his time between the care of his ninety-year-old grandmother, Margaret, and his carer Roy, still attending a local work centre, still known across Hastings by an astonishing number of people. Front-line workers, shop staff, strangers in passing—many know him simply because joy seems to travel with him wherever he goes.

> What people notice first is not disability, but delight.

He has never lost the gentleness described in these pages as a child. He remains gracious, eager to help, quick with wordplay, and capable of producing unexpectedly sharp little Latin quotations with comic precision. He rarely complains. There is about him a beauty and lightness difficult to explain except to say that some people seem to carry peace unusually close to the surface.

His faith remains sincere and unforced. Never loud, never theatrical, but steady and deeply rooted. Music given to comfort him as a broken child has long since become praise returned to God.

Margaret is now eighty-nine years old and still faithfully cares for him. Perhaps that is the final astonishment of this story. In those first terrible hospital days, no one was imagining forty-four more years. No one imagined laughter carrying through decades. No one imagined such fullness of life.

And yet, here it is.