

THE SUNFLOWER OF OUR LIVES



JEAN - A FAMILY'S INSPIRATION



Jean was born on 6 June 1955, sister to John, age three and Mary, age six.

My wife, Margaret, and I had married in 1948 and I had joined the Royal Army Medical Corps as a nurse in 1954.

Jean was born at home, in Cowley, a civilian house rented to the army. I was privileged to be present at the birth. Mary and John soon shared in the joy of their baby sister – a happy and contented baby, she was adored from the word ‘go’.

We were a happy family. My career was going well; I was now a Corporal and working on a neurosurgery ward, gaining lots of experience. Then, in November, I received news that I was to be posted the following year, to the British Military Hospital in Nicosia, Cyprus.

We spent that Christmas at my parents’ farm in Sussex. The festive period was a time of great rejoicing, as we had two new babies in the family. Margaret’s brother and his wife had had a son, Paul, a few days before Jean was born.

Previous to that visit, Margaret and I had had some doubts related to the fact that Jean might not be thriving well. So we could not help comparing her progress with that of our nephew, Paul.

In February, the doctor at the clinic asked to come and see Margaret and me. As gently as he could, and with great sensitivity, he told us that Jean was a ‘Mongol’ (the term ‘Down’s syndrome’ came much later). He then explained to us what that meant.

Not only were we devastated, we knew so very little about the condition. There was not the same information and support given to parents in those days. Instead, we were given a little twenty page booklet entitled 'For the Parents of a Mongol Child'.*

However, Jean was an integral part of our family and any thought of leaving her behind in an institution was swiftly dispelled. We sought a second opinion from the paediatrician at the hospital where I worked and, when he confirmed the diagnosis, Margaret and I felt that we had been privileged to be chosen to care for one of God's precious ones.

People who knew us were very kind and supportive. We also had some lovely, uplifting letters which were to sustain us in the years ahead.

I flew to Cyprus in March 1956 and Margaret brought the three children out in June.

Cyprus, while a lovely island, was no Mediterranean paradise in the mid fifties. The EOKA terrorist campaign to end British rule and achieve union with Greece was at its height. This meant that British service people and their families lived under constant threat.

Jean had been sick a lot since I left the UK and it took all Margaret's skill to keep her from becoming dehydrated. But – it's strange – within a week of being in Cyprus Jean's sickness had passed and she started to put on weight. However, within a month she developed pneumonia. The families' doctor at the clinic said, "I can give her antibiotics; they might help, but you know the weakness of these children. Alternatively, we could treat her. She might make it, but she might not. What do you want me to do?"

There was no question, no doubt: Jean had to be treated. How could we sit back and watch this lovely child's life being destroyed simply

because we wanted her to die ... or ... because we were afraid of the life-long responsibility? How could we live with that?

This was the real issue.

While we appreciated the doctor's compassion, we knew our choice was right.

Jean recovered from her illness, but over the next three years, had two further attacks of pneumonia. Little did we know, then, just how determined a character she was, or what a delightful lady she would become.

Jean travelled the world with us until 1971. I was getting on towards retirement from the Army and, not knowing where we would be, we decided to put Jean in care. She was very happy and, although she came home to us every month, she was always keen to return to her friends. She joined the Trefoil Guild of the Girl Guides, which she loved, and Margaret and I joined them at camp, where I played the accordion and at their Christmas concerts where I played the piano.

In 1977 Jean moved to a brand new hostel in our village. This meant she could come home at weekends. Jean now lives in a bungalow very near to us with two (special needs) friends and their wonderful carers. She comes home every other Sunday. In between those visits, she goes to parties, discos, and on holiday to all sorts of places. Truly, Jean enjoys her life!

Those are the facts; but what they don't tell is how Jean, although severely disabled, has enriched our lives.

We no longer took for granted milestones which our other children reached, as they grew up.

Also, as parents, we were unaware of the depth of the relationship between Jean and her siblings, until we read the poem, Jeannie, by her sister Mary.

For me, knowing Jean has been a privilege beyond words. She is the epitome of genuineness, empathy, and acceptance. She doesn't judge anyone. These are all qualities I have had to work hard to develop as a therapist ... yet they come naturally to Jean.

None of us is perfect. Some look at Jean and think she is not normal. Well, she may not be like us, but what is normality?

Jean will soon be fifty four. Although she is showing signs of ageing, she still touches the lives of many people with a deep spirituality that surpasses anything of this world's learning.

Thank you, Jean, for allowing us to share your life and for being such an inspiration.

Your Dad



When I came home from school, that day in June, there was a new baby, Jean. I remember the house being full of excitement. I recall, too, over the next few months, the aura of worry and concern And I remember, vividly, the day in February when I said to my mother, as she walked me to school,

“Mum, when I grow up I want to have a Mongol baby as well.”

All of Jean's siblings accepted her without question. They would have died defending her. But we did not have to do much as Jean's sunny disposition meant that she was readily accepted by our friends, too.

Occasionally one of the boys would get into a scrap because one of his peers had made a derogatory comment about 'Mongols'.

Also, I remember a debate at college on euthanasia. On that occasion, I was so rattled by a girl who stated that all 'subnormal' people should be euthanised that, even though I was terribly shy about speaking in public, I felt I had no choice; I had to stand up and 'say my piece' ... to subsequent applause.

Jean taught us compassion and patience, particularly when encountering those who were less fortunate or different in some way.

As she grew up, Jean's developing sense of humour was awesome – as was her dislike of argument or squabbling. This resulted in her becoming the family mediator and respected for this valued role she played.

My father mentions the little booklet which my parents were given. I have it still. The author, who dedicated it to 'The most charming little people in the world', wrote, in 1946:

'They bear no grudge but meet life afresh at every moment. It is here that we ourselves can learn much from the Mongol child. His natural warmth, his certainty of the fundamental goodness of life and of humanity, his capacity for utter forgiveness; all these are things for which we could well strive....for us, this true and natural approach to life is extremely difficult, because we have become so hard and so intellectual in our outlook...our boasted intellect thus becomes a stony barrier, interposed between ourselves and other people.'*

I can't add to that. It says it all ... Except to say:

"Jeannie, it's a privilege to call you my sister".

Mary

* For the Parents of a Mongol Child, May 1946, author 'I.N.' issued by Sunfield Children's Homes, Clent, Stourbridge, West

Midlands

JEANNIE

When you were born I planned our life thereafter
A sister to share fun, dresses and laughter
But you had something extra, a chromosome
It made you a Mongol, now called Down's syndrome

I looked at you often when I was a child
And wondered; before this, before you beguiled
Us with your charm, your innocent fascination,
Did you have, somewhere else, an incarnation?

You sat in your big armchair, I held your hand.
Sometimes you seemed to be away in a land
We couldn't reach, couldn't read the sign-posts.
You smiled. To yourself or to angels in hosts?

You loved music, anything with a good beat.
With your arms lightly folded, your legs and feet
Forming the lotus position, your smile big,
You started to rock or, as we called it, jig

When you knew we observed from behind a book

You started to giggle till your body shook

When we glanced from the table once in a while

You knew it was time to tease or use a wile

On Sunday mornings into my bed you'd crawl

I'd say, 'I've got big legs but yours are so small.'

You'd squeal to hear me say it and, if in jest

I'd pretend to forget, you'd give me no rest

We siblings used to marvel at your great art
For memorising pop music off by heart
“What a waste. She’d have been so bright,” we’d bemoan.
Was that fair? Only you know, and you alone

While we, all round you, hustled and bustled
You sat serene; glossy pages just rustled.
When there were rows and the trouble was deep
You stopped it instantly by starting to weep

As we grew older you were always around
We were protective, keeping you safe and sound
Then one day you went to a home called Park Gate
In a way then, we lost you, our little mate

You’re always my sister, always on my mind
So much happier now that you’re with your own kind
Institutional living is long since gone
In its place bungalow, housemates, disco, song

We never thought you to make much past fifty

Down's folk get worn out; God takes them up swiftly
Still many years yet, I hope, but when you're at rest,
I'll look back and say, "Jeannie, you were the best".

TRIBUTES TO JEAN FROM HER BROTHERS

Her elder brother, John, in the United States:

Jean taught me tolerance



The elder of Jean's younger brothers, Peter:

Long before I was born the Creator of the Universe had a plan.

Part of that plan was for June the 6th, 1955 when the person I knew as "Jean" was born.

But another, equally important part, of that plan was for 10 o'clock on the morning of October the 8th, 2009 when Jean was called away from this earthly life. Such precise timing was understandable considering Jean was always very particular about the time.

On that special day the sun shone brightly for Jean and it was quiet and peaceful at the bungalow.

But more wonderful things were destined!

I was lucky enough to witness one of them – along with the carers who were present – and I will never forget the moment when the undertakers arrived.

No sooner had they rung the bell and the door was opened than suddenly the small group of birds, hiding in the rose bush by the front door, broke the silence by chirruping as loudly as possible. They kept this frenzied singing going for half an hour until it was time for the undertakers to drive away. And at that very moment

the birds stopped singing as suddenly as they'd begun. All of us were amazed but perhaps we shouldn't have been!

Other special things happened on that day – and special things will happen today if we look out for them.

Certainly on *this* day I can happily say, I still *know* Jean!



The youngest of Jean's brothers, David, also in the USA

Little Big Sister, Sunflower

Today a sunflower rests upon you, Jean, little big sister. Warmth and brightness are in the petals of it, but there is a potent pliancy in its entirety, too, a strong delicacy, a forceful yielding. And, of course, there is the joyous music of it. All these qualities you had, Jean, all. You were a sunflower personified.

Friendship and reconciliation were the essence of you, as well. You were the one who mediated, the one who befriended, the one who made peace. You improved everyone you touched – an achievement none of us remaining dare boast for ourselves.

Although you have physically left us, the inner being of you will not fade like the sunflower that rests upon you today. Your spirit will shine on within us, all those you knew, for as long as we live. I send my deepest love and thanks to you now, little big sister, Jean, but I will not say farewell, as no farewell is required, now or ever.



JEAN - A GIFT TO US ALL

Following publication of the article *Jean – A Family’s Inspiration*, in the Spring edition of *The Living Document*, William, Margaret and all the family were deeply touched by the wonderful messages received from many of William’s students who themselves had been uplifted and inspired by the story of his Down’s syndrome daughter, Jean.

The line in the poem, *Jeannie*, written by William’s elder daughter, Mary – ‘Down’s folk get worn out: God takes them up swiftly’ – proved, indeed, to be so. Jean died on 8th October, peacefully, at home in her little bungalow.

She had been diagnosed, only at the beginning of September, with cancer of the gall-bladder, following a very short spell of not wanting to eat – most unusual as she adored her food and so everyone knew that something was amiss.

Jean went into hospital for three weeks, initially for tests and subsequently for treatments for the jaundice which had developed. While there, she wove her magic, still. Staff and patients alike were encouraged and inspired by her friendliness, innate compassion, gentleness and by her zest for life. Touching words came from the Registrar at the end of his discharge report – ‘this lovely lady has been discharged home to palliative care.’

Jean chose her own time to leave this world. A morning, in between grey days, when the sun shone brilliantly; at a time when the early

morning hubbub at the bungalow had subsided and all was calm and peaceful; when two of her special carers, Pauline and Andrea, were sitting at either side of her bed, holding her hands and talking softly to her. She passed, still with that magical smile on her lips.

At her funeral, to the 100-strong gathering, Paul, the Minister read 'Jean – A Family's Inspiration' and the poem 'Jeannie'. Mary read the tributes; truly lovely eulogies from Jean's three brothers, John, Peter, and David, and these moving words from her extended family of friends and carers:

One of the things which gave Jean great pleasure was looking through her old photograph albums. She would sit for ages ploughing through pictures that spanned 54 years. They told a story of the happy times she had spent throughout her lifetime and gave her great comfort right to the end.

When looking at pictures of her family and her friends, past and present, she would name everyone and giggle with joy. Remembering the people she held so dear, even her friends who are no longer with us, tears would fill her eyes and she would say "happy tears" and give a big smile.

A lot of people here today are in those photographs and will have their own happy memories of Jean. She was a very special person who touched many of our lives.

Today should be a day to celebrate her life.

No tears of sadness – just 'happy tears'.

Your love was like the dawn

Brightening over our lives

You placed smiles like flowers

On the altar of our hearts

Look around your garden, Lord, and

When she turns and smiles,

Put your arms around her,

And hold her for a while

Wonderful and touching words were spoken to the family by so many people who knew Jean, and little stories and anecdotes are emerging of a person with an extraordinary spirituality laced with an abounding sense of humour.

Our deepest love and thanks to you, Jean – you have been a gift to us all.

