

Pacific caring

A snapshot of the life of Alfred Manaseli Hartnell.

By Richard Pamatatau

Memories of Alfred

My cousin Alfred was profoundly disabled from birth – though my Grand Aunt Ruth Hartnell and her husband, Uncle George, had no idea of this on the day he arrived.

He was, my cousin Lola Hartnell tells me, healthy, plump and noisy.

No one knew that he would have extra needs till he was about six months old.

Then, as he got older, bit by bit the complex issues he would face throughout his life began to materialise.

Lola and her sister, Frances Hartnell, were at this time too young to know much about their brother's disabilities.

The detail of Alfred's impairments has been lost in the mist of family memories, which both anchor us to a point in time, and ironically set us free.

What I remember from an early age (I am now almost 50) is that Alfred was part and parcel of every family event at my Aunt and Uncle's busy, busy Ponsonby house throughout our lives.

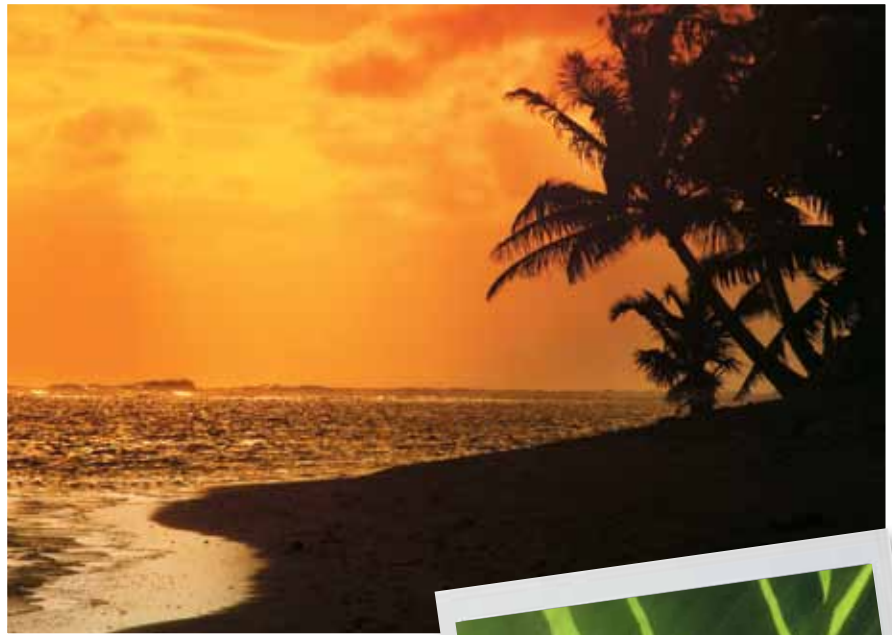
Why was their house busy, though?

What set it apart?

Caring, Pacific style

My Aunt was from a large Pacific Island family.

This meant that there were always people



in the house – visitors on the way to or on the way back from the Islands or other parts of the country.

My Uncle George, who was European, had a wide circle of friends, so the two lounge rooms in the Albany Road house were needed and well used, with people spilling from one to the other.

Then there were the family events, which involved lots of conversation, food (of course), singing ... and, always in the fray, Alfred. Often he would be propped up on cushions in the midst of proceedings, if not snuggled into or between family and friends.

Bear in mind that in his later years we are talking about a 40-something man, who was well aware you were there even if you didn't know how he recognised you.

Lola tells me that her parents were adamant Alfred would never 'go into a home', which was then the fate of many disabled New Zealanders.

"Our parents would never have allowed it," says Lois, and thus Alfred never did shift to another home of any kind – other than the homes of other family members.

Getting acquainted

My first memory of Alfred is when I was about six or seven – young enough to be



both curious about and fearful of disability.

I recall not wanting to go into the lounge room where Alfred was holding court with other members of the family.

My Aunt Ruth said, "Richard, come in here and say hello to your cousin."

I was petrified, especially when I was instructed to give Alfred a kiss and a hug.

Of course I did – nervously – but after that moment Alfred was, to me, just part of the family furniture ... another cousin at our large family functions.



Lola says her parents worked very hard to look after her brother.

His care needs were demanding, but she has no recollection of there being any grumbling or resentment.

"We all just saw supporting him as what we did as a family," she says.

"For my sister and I, when we were older, we supported Alfred too. Alfred was our brother and caring is what you did, without question."

At the time some may have said that Alfred's care needs may well have been better provided by an institution.

But Lola says if Alfred needed to be changed, fed, washed or walked, "we happily did those things".

I asked her what it was like having a brother who was unable to respond in a conversational way.

Lola says this never mattered, as the family knew Alfred knew he was loved. He knew each one of them, and that was enough.

Of course both Aunt Ruth and Uncle George worked for much of Alfred's life – and so for large periods of time his care during the day was given by his Grandmother, who also lived with the family, with assistance from other relations who had the time to help.

My Aunt had trained as a masseuse and I can remember her gently massaging Alfred in a bid to keep him mobile – there were times when he seemed to be curling up – but her relentless body work kept him going.

He was also kept meticulously clean, and rarely got sick.

The washing machine seemed to go nonstop, though, and the shower was adapted for his needs.

I also remember Uncle George spending lots of time with his son while my Aunt was fulfilling her many community obligations.

Human kindness

I recall a Christmas some 15 years ago where Alfred was having an early Christmas dinner and being fed by a cousin who is now a tax lawyer in London.

We were talking about some political issue, but at the same time she was feeding her uncle. Supporting him was a seamless and shared family commitment.

Another thing Lola reminds me of is that Alfred was well travelled.

My Uncle and Aunt kept a house in the Cook Islands, and Alfred often spent winters there when they escaped the wet and cold of Auckland for the warmth of Rarotonga.

Lola says there was never any question

"MY AUNT TRAINED AS A MASSEUSE AND I CAN REMEMBER HER GENTLY MASSAGING ALFRED IN A BID TO KEEP HIM MOBILE ... HER RELENTLESS WORK KEPT HIM GOING."

that Alfred would be left behind – and no reason to do so.

As my Aunt and Uncle got older, Lola says her father was worried about who would look after Alfred if either or both of them died before he did.

Uncle George told Lola Alfred would have to go into an institution if that happened.

Lola says if the need had arisen, the family would have continued caring for Alfred.

"He was our brother and we would have looked after him – it wasn't a particularly Pacific thing, it was just a human thing, and we had the resources to do it."

As it happened, Alfred died before both of his parents, and his funeral was a celebration of a life lived well through the support of family.

Lola also says that while growing up there was no shame about having a disabled brother, or bullying from others.

"We never had those issues. We do recall not having as much time from our parents, but it was also obvious that Alfred needed their time and attention, and that was the end of the story."

Family values

For me, as an observer and someone who shares Alfred's second name, it is difficult to say much more.

But from ongoing conversations with

members of the family, what seems to have established itself as an ethos amongst us is that while caring for a loved relation can be tough, time-consuming and difficult, the returns cannot be measured.

What is also clear is that the value of such round-the-clock care, if it was measured, would be very costly.

That is something any government must consider when it evaluates the role of the many family caregivers who work so hard right across the country.

