



Monthly News • October 2013

Tena Koutou, Talofa Lava, Kia Orana, Fakaalofa Lahi Atu, Malo e Lelei,
Bula Vinaka, Taloha Ni, Kam Na Mauri, Greetings to all!



Data base: 5455 Whanau Carers.

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From the National Office:

My Nan, My Strength:

The veins stand out on her hands. Her hair although faded, still shows traces of the red that was, and her face has lines now. Sometimes I

wonder if I'm responsible for those.

She's 60, yet still gets up at the crack of dawn, lights the fire and chops wood so I can have a hot shower when I awake. Other times she wakes me with a creamy hot chocolate like she's done since I was little, so to me, chocolate tastes like love. She's strong in every way that matters - and never lets me down.

She is my Nan and my strength.

It's been a year now since my legs failed me and three since my sanity lurched, but Nan has always stood by me. She's carried me: helped me dress, and helped me dig deep to find the strength to carry on. It's been hard too because staying alive hasn't been where I've wanted to be - and if I'm honest - it's sometimes still hard and suicide seems my only option. Yet we talk and it passes. So I know if I died, I'd be lonely without her, because as long as I remember she's been there beside me. She's

My Nan - My Strength.

While I'm creative – so is my Nan, and she's worked hard digging, sanding, painting and decorating to make our home and garden special. With friends, family and strangers, she's equally kind and generous. But her sense of humour is wicked so I guess that makes her a mix of funny and unpredictable too. To me she's simply 'My Nanny', warm and toasty like a marshmallow fresh out of the fire. Outside strong, while the inside's warm, soft and gooey.

My marshmallow, My Nan - My Strength.

Thinking back, our home has always been full. Sometimes people came, stayed and grew to become family, like the Aunties (Angie and Liz), who arrived as lost teens and who now

have teens of their own. Then there have been people who are not from New Zealand who Nan picked up from the road side and brought home. Sometimes for a meal, or for 'a coffee', while steaming damp shoes and clothes dried by the fire, other times, for a night or so. Regardless, such are my memories. Me and Nan there in the middle: surrounded by lots of warmth, laughter, a multitude of faces, voices (not always English), hot food and always this very strong sense, of rightness.

My Nan - Always there. Our Strength. Fe Isaako aged 18

Grandma says

“Because day in - day out we all gladly do what needs to be done for our little-es, yet how often do we stop to think that we're actually in the business of 'making memories'. I know I never gave it a thought. Yet these are Fe's memories and I feel blessed that they are what they are.

THE STORY OF RYAN

To start Ryan's story I have to go back to late November 2000. Our 25 year old son came home with a new girlfriend and announced they were getting married! My husband and I were not happy but he was 25 and there was little we could do. It turned out she was attempting to get residency and fighting to stay in NZ. She thought that by marrying a kiwi she got automatic residency, but when she found out that was not the case she left our son. To complicate matters ...she was pregnant.



Ryan was born on 20th September 2001. He was born perfect. Christmas 2001, his mother, and maternal grandmother came to see us with this gorgeous boy....the image of his father! His mother told us in no uncertain terms that we would never have anything to do with him again as he was nothing to do with us and she only came because her mother had forced her to.

We heard nothing more from them until I received a phone call from his distraught maternal Grandmother on Friday 15th March.

Ryan had been taken to Starship on Monday 11th March 2002 with a severe head injury. He was 5 ½ months old. He had not returned to full consciousness, had a bruise on his forehead, acute subdural bleeding and extensive bleeding into the retinas of both eyes (which was to leave him cortically blind). He had violent convulsions for some days before they were brought under control. He suffered a stroke. He had been accompanied by his mothers' de facto partner of 3 months. His mother had left him with the partner when she went to work, he was supposed to take him to child care. He had offered several explanations of what happened from the dog had knocked the baby over, then it was a cat...then he had thrown Ryan in the air and dropped him.

Pat Kelly and Justin Mora (Starship) reported Ryan's injuries were consistent with being shaken...there was also previous brain injury (subdural hematoma) that could not be dated.

Ryan had also had previous injuries that had noted....bruising around his ear (from tearing his clothes over his head, a burn on his thumb....he had touched a hot chip????)

In the days following Ryan's "accident" his mother and her partner were "visiting" Ryan ...This did not sit well with nursing staff or CYFS. His mother told hospital staff no one else was to visit Ryan....especially her mother and me! Next thing Ryan is put under CYFs care ...after 4 weeks in hospital he was sent to the Wilson Centre for rehab. His mother hardly visited him and so I started going daily.....he was the image of his father, my son.

CyFS asked if I would be willing to take Ryan home when his rehab was finishedmy husband said only if it was proven that Ryan was ours...no one else in the family had seen him only I knew he was the image of his father.....so DNA testing was done and it was a fact...Ryan did belong!

We asked our kids who were still at home (3 of them at the time) if it was ok to have himespecially our youngest son (13 at the time) who would have to give up his role as the youngest.....Ryan came home to us on July 11th 2002. We were told this is probably the best Ryan will be ...expect no improvement.



I had to give up working.

When he came to us he was like either a stiff board or so floppy like a newborn you could do nothing with him, he would not snuggle in. I had been doing a lot of Google research on the net and found the Mozart theory (play Mozart to babies and it sets their brains working) and also patterning and sitting in the dark with a bright light shining on my face for him to "look "at. So I lived like a bat in a cave sat on the lazyboy listening to Mozart trying to snuggle a

child that did not want to be snuggled with a light shining at my face...with the help of the family I might add....this went on for almost a year before he finally snuggled and smiled intentionally at my face!

Since then we have shared guardianship with his mother, although she has probably has only seen him a couple of dozen times at her mother's house. She stopped coming to our house when she was told someone had to stay with her while she saw Ryan. Ryan's abuser went to court.....and got a term of 2 years jail...he had a couple of nights at Mt Eden where he was on suicide watch, then he was sent to a prison farm down south. He served about 4 months there...he then got home detention for 4 months ...he is now off scot free to get on with his life, while Ryan and my husband and I suffer a life sentence for the rest of our lives.

Ryan comes under ACC (we think because his abuser "accidentally dropped him") so funding for things is not a problem luckily. We have had a lift put in at home to help my back.....also

fencing in the garden to stop Ryan having access to a pond. My husband and I are paid an hourly rate to look after Ryan for about 10 hours a day (not sure who looks after him the other 14 hours!!) This is less than minimum wage and taxed and has ACC charges as well! We receive an unsupported child benefit for Ryan and Ryan has a disability benefit. Ryan has had a payout from ACC of about \$75 a week till he is 16....this is what his life is worth

The shaking that Ryan received has caused him to be globally delayed. Shaking damages the brain at the front and backsight and speech in particular....At present he is 12 years old chronologically...but developmentally only about 3 years old. He has a left haemeaplegia and is cortically blind. He is language delayeda lot of what he says is babble although he does have a couple of dozen real words! You can sometimes decipher what he says by looking at it in context. He has in the last 4 months managed to toilet train, but is still in nappies at night....not pleasant at that age, for him ...or us!!

Ryan is very musical....he goes to Raukatauri Music Therapy Centre once a week which was paid for by ACC, now they are saying they may not fund this in the future as ACC does not see the benefits of Music Therapy.....he now shares a lesson with Daniel who has similar injuries caused by problems at birth. He can hold a tune, "sing" along to songs (into Queen at the moment) and beat in time. Not bad at all!!

Ryan is very temperamental and damages things unintentionally! We go thru fans, heaters, cell phones, iPods, radios, cd players, TVs, CDs, DVDs, cameras, video players and DVD players all of which hold a fascination for him. He will be beating out a tune on the table and "dinging" the wood.

We have given up trying to keep him away from things. We do however have few knobs on doors in our house. This is to limit the number of rooms Ryan can access at night in particular when we try to asleep. We used to wake up to TV, heater, lights, computer, radio etc all on!!!! Ryan only sleeps about 5-6 hours a night if we are lucky.

Ryan attended Coatesville Playcentre till he was 6. I did try Ryan at Dairy Flat School for a year, but it really didn't work. I was glad I went in, as the teacher aide as I could see it didn't work and did not have to wonder if things could have been different. I homeschooled Ryan until February 2013.

MILESTONES

2003 (aged 2) Learnt to sit alonecrawl...pull himself up to stand against furniture all things we were told he would never do!!

2004 (aged 3) In March it was 2 years since the injury. July saw Ryan's guardianship approved by the court. Ryan can climb out of the cot, so we took the side of the cot now he crawls out at night and explores the house! Fencing was done outside as he is a menace when he escapes. Ryan achieves new heights...he has learnt to climb....stairs, furniture you name it! Ryan started Coatesville Playcentre. Window film put on all lower



windows....

BEST NEWS Oct, Ryan walks with a light hand hold !!

2005 (aged 4) April....going off Tegretol, had no epileptic fits for 2 years. In May, started Melatonin to help with sleeping ☺ also in May, a lift put in. Ryan pulls his toy train on a string!

2007 (age 6) Ryan started dairy Flat Primary 1 ½ hours for 3 days a week, April he was botoxed, July burnt his hand on the iron...we got a gate fixed on the laundry, front door and door at the top of the stairs

2008 (age 7) Swimming lessons....May, started home schooling Ryan learnt to say please and thank you! August Ryan lost front tooth, Ryan can reach lift buttons...have secret button installed so he can't escape! Have to stop swim lessons as we cannot afford them. He has to have one on one as he could accidentally drown another child.

2009 (age 8) Ryan was given "The bangs" (an old Lowery organ!!) February Ryan had a big tendon transfer op and botox. May: learnt to put his fingers in his ears when in trouble or does not want to listen! August, "Circle chairs" (office chairs!) November: botoxed again.

2010 (age 9) had to get rid of the bangs! ACC not going to fund music therapy I am fighting them. Botox Sept 15th under General Anesthetic, did not work well. He has finally learnt to feed himself.

2012 Just before Christmas Ryan started having seizures again, so he is back on medication. This makes him tired and grumpygreat!!!

2013 (age 11) after homeschooling all these years I finally gave in and sent Ryan to school, Albany Junior High special unit. He gets a bug in his system from school sores which plague us for 6 months. He is still botoxed and having his teeth done under a general anesthesia yearly. He has been to the GP more this year than all the years we have had him!! Gerny schools!!!!

Our biggest problem, if you can call it that, at the moment, aside from the unintentional damage Ryan causes, is finding a babysitter for Ryan. You can't leave him with the kid up the road!! Our own children who have been his unpaid carers now have their own families and lives.

I always thought once my kids were grown up and off my hands I would have time for meJust before we got Ryan Blake and I had just started date night once a week.....Me time is now few and far between...as is relationship time for my husband and I (Ryan ends up in our bed most nights about 2 o'clock in the morning, if we are lucky he will sleep for a while, recently he stays in his own bed, when not wandering the hallway !!) Time for other grandchildren is limited as well.....Ryan is rough and can't be trusted with other children on his ownmy oldest granddaughter rarely comes to stay as she gets scared of Ryan. My daughter has twins one is medically fragile. I was lucky Blake was working from home so he took over Ryan duties so I could help. We have two grandchildren in Australia, and we have never seen/met the youngest.

Don't get me wrong it is not all doom and gloom! We have had many funny incidentsthe oil.....the angel wings in the milo incident, the M&Ms incident and the fire alarm while on holiday in Rotorua come to mind !!! If he comes up to us with his fingers in his earswe know, oh – oh something has happened!!

Never shake a baby

YouTube "Never shake a baby" video featuring two of our grandparent members - courtesy of Starship Foundation. Click on the link below to view the video: Or go to our web site www.grg.org.na

http://www.youtube.com/watch?v=GMG5sG_A4Fg

Power to Protect - the link below will take you to the MSD Power To Protect site for valuable information and helpful on what to do if you think a baby has been shaken.

<http://www.powertoprotect.net.nz/ask-for-help/index.html>



What is going on here then?

Trish (our GRG beneficiaries' advocate) and Di now regularly travel to Wellington to discuss your many trials and tribulations with the head office of W & I MSD. Of all days we had to go we heard there were gale force winds in Wellington. Well we surfed from side to side into Wellington, as we looked around the very full plane people were hanging on to the seats in front of them, there was no actual screaming, but low audible groans could be heard. It was very scary, we got a more than a bit of a sweat up; there was huge round of applause when we landed. The wonderful pilots were at the door smiling and Trish had to contain herself and

not kiss them. They were so awesome; trouble was we had to come back that same afternoon. As you can see by the picture the plane was almost empty, most people had bailed we suspected, this was a most violent shaking up and down of the plane this time and yes that is the sick bag I am holding. These winds must have followed us up as we had the same when we hit Auckland. So two, very pale faced grannies were very glad to be home.

We had both survived to fight another day, whew!!!

Carer Support Days;

What is Carer Support?

Carer Support is a subsidy funded by the Ministry of Health. It is designed to assist the unpaid full-time carer of a disabled person to take a break from caring for that person. Carer support provides reimbursement of some of the costs of using a support person to care and support the disabled person. This means the full-time carer can take some time out for themselves. The number of hours or days that carer support is funded for is determined by the needs of the carer and the disabled person.

Who is a full-time carer?

A full time carer is the person who provides more than 4 hours per day unpaid care to a disabled person, for example, the parent of a disabled child/grandchild

How do I get Carer Support?

You can be assessed by a Needs Assessment Service Co-ordination (NASC) organisation or, in some circumstances, by a doctor. They will then allocate your Carer Support days and undertake a review with you, usually after a year. You can self refer.

How can I use my Carer Support?

Carer Support is designed to be flexible and can be paid to friends, some family members or neighbours who provide relief care or to people who provide relief care in a formal setting, for example a rest home.

Carer Support cannot be used:

- While the full-time carer is at work
- By the parent or partner of the disabled person
- To convalesce after discharge from hospital
- If the support carer lives at the same address as the full-time carer.

What are Carer Support payments regarded as?

Carer Support payments may be subject to income tax. This will depend on your individual circumstances. You may wish to seek advice regarding tax issues from the Inland Revenue Department, or if you receive a benefit, you should contact Work and Income New Zealand.

Where can I get more information?

You can contact your local NASC. Contact details can be found online at www.health.govt.nz/disability under 'contact'. Your doctor or health professional should also be able to refer you to your local NASC.

A disability information service will also be able to help you find your local NASC and give you information. The New Zealand Federation of Disability Information Centres (NZFDIC) has several member organisations throughout New Zealand. You can contact them on free phone 0800 NZFDIC (0800 693 342) or online at www.nzfdic.org.nz under members.



Great Grandma with her great grand-daughter:

Aim for the moon in life and if you miss and fall into the darkness, you will be a star; do not be afraid of the darkness for this is when stars shine the brightest.

Legal Aid:

Talk about kicking one when they are down. Hot on the tail of those of us on benefits being made to work comes a letter from Legal Aid telling (those of us that had to use this to keep an at risk child safe,) that they will now incur an **8%** interest charge! It is not like they can go to a bank and get a 5.25% loan, if that was the case they would not have needed legal aid in the beginning. And you know who will suffer in all of this yet again, don't you folks, yep the children. Grrrrrr

Legal aid repayments

Legal aid is government funding to pay for a lawyer for people who cannot afford one, and need one in the interests of justice. People who get legal aid may have to repay part or all of their legal aid costs. Interest will be charged six months after your case has been finalised at the rate of 8%.

You may have to repay some or all of your legal aid, depending on how much you earn, what property you own and whether you receive any money or property as a result of your case.

The financial information you give on your application form is used to work out whether you have to repay anything. When you are told that you have been granted legal aid, you will be told the maximum amount you may have to repay.

How do I make repayments?

You can be required to make repayments in different ways, and you might have to pay in more than one way:

- through regular payments (instalments) made weekly, fortnightly or monthly
- as a lump sum, either out of your savings or when you sell your house or other property
- any money or property that you keep or get from your court case (civil and family cases).

If you are required to make regular payments, you may have to start them straight away. An automatic payment form will be sent to you to help you to get these payments started.

Problems with repayment

If you do not keep up with the repayment plan, a deduction notice may be imposed on your debt or the debt can be outsourced to a debt collection agency.

If you have problems meeting your repayments, contact the legal aid Debt Management Group on 0800 600 090 as soon as possible.

Your repayment plan may be changed or put on hold. In some cases, some or all of your legal aid debt can be written off (cancelled) if you can't repay it. You can ask for your legal aid to be stopped, but you may still have to repay some or all of the aid spent so far.

Securing legal aid debt against property you own

If you own a house, car or other valuable property, you may have to authorise a charge on the property as security for the debt. The charge means that if you sell the property, you must repay your debt out of the money you get from the sale. You may be required to make regular payments, even if your debt is secured.

Hot tip of the month:



To save on your power bill use an automatic on/off timer to ensure you're only using your heater when you really need it. Many heaters have built in timers but if yours doesn't you could use a separate timer. Also make sure you put a

guard around your heater if you have kids or animals running about to keep them at least a metre away.

The Woes and Pros:

Of raising grandchildren: Young 11 year old had been on my computer and had downloaded something I could not get rid of and he had also deleted all my normal programmes. Help! 21 year old grand-daughter came to the rescue she deleted this new item and many other ones he had downloaded.



The next minute I looked over and saw that she has my computer key board on the kitchen bench, with a kitchen knife she was popping out all the keys, they were flying everywhere. And she gathered them up and popped them into a bowl of hot soapy water. "Nan, come here" she called, "how can you type with the keys sticking and just look at all this gook on the base", she said pointing to the now totally de-nuded key board. In my defense I said, 'but this is where I drink my coffee and tea and eat my lunch!

The roll of the eyes said it all. I had no idea you could pop off all the keys and what now worried me, was, how would she know the order in which to put them back. But as you can see I am able to type this anecdote correctly and the next morning, bleary eyed with my coffee in hand on my key board I found a note: 'No eating or drinking here' sitting on my now very clean keyboard.

Peach cake:

1 large can sliced peaches, drained and mashed (I used 2 regular cans since that is all I had at the time) You could also use fresh peaches.

2 cups all-purpose flour: 2 cups sugar:2 teaspoons baking soda: Drain the peaches and empty into a large bowl. I just used my hands to mash them.

Add flour, sugar and soda and mix well. Spray a 9 x 13 inch cake pan and pour in batter. Bake in a preheated 350F degree oven for 35 minutes. See recipe below for icing.

ICING:

- 3/4 cup sugar:
- 3/4 regular sized can of evaporated milk:
- 1 stick butter or margarine
- 1 cup coconut (I used a little more than a cup of coconut)
- 1 cup nuts

Boil everything but the nuts on top of the stove until thickens, remove from heat, stir in nuts and spread on cooled cake.

Member Support Manager: Di & team (as a caregiver you are part of our team)

heoi ano, na. *E te Atua, aroha mai..... O God shower us with love. Ka kite*

Please feel free to send/email this report on to others whom you think may be interested.

Please pass this on to other grandparents/kin carers you know of.

GRG Trust Head Office hours are 8am – 2pm daily.
(We raise grandchildren too)

Views expressed in this newsletter may not be the views of the GRG Trust.

We are a voluntary not-for-profit organisation.
All donations to the GRG Trust are tax deductible.

Grandparents Raising Grandchildren Trust NZ Mitre
10 Community of the Year 2013



Karakia

*Kia hora te marino
Kia whakapapa pounamu te moana
Hei huarahi mā tātou i te rangi nei
Aroha atu, aroha mai
Tātou i a tātou katoa
Hui e! Tāiki e!*

*May peace be widespread
May the sea be like greenstone
A pathway for us all this day
Let us show respect for each other
For one another
Bind us all together!*

