

A close-up photograph of two hands, one from the left and one from the right, with fingers interlaced to form a heart shape. The skin is light-toned and shows some texture, particularly on the fingers. The background is a soft, out-of-focus light color.

The Art of Great Care

**Stories from people who have
experienced great care**

He aha te mea nui?

He tangata.

He tangata.

He tangata.

**What is the most important thing? It is people,
it is people, it is people.**

**The generosity and good will of the consumers
who have shared their stories to help other
consumers to receive great care is once again
gratefully acknowledged.**

Compiled by the Nationwide Health & Disability
Consumer Advocacy Service

Officially launched by Ron Paterson, Health and Disability Commissioner,
on 15 March 2010 at the National Health and Disability Advocacy
Conference in Auckland

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Introduction

The Health and Disability Commissioner, Deputy Commissioners and the advocacy service have been collecting and using great care stories since a public invitation in 2006 for stories of what care looked like when it worked well. This resulted in the launch of the first booklet of great care stories at the *Putting Patients First* conference on 18 April 2007.

We specifically invited people who have experienced great care and are willing to allow their anonymised story to be used for education and training purposes to either send in their story or to tell their story to a health and disability advocate who would write it up on their behalf.

The stories are being used to promote a focus on quality as described by people who have received great care. They have proved to be a very effective way of showing providers what consumer-centred care looks like. Some stories have already prompted quality improvements.

This publication includes the fourteen stories from book one, the twenty-three stories from book two and twenty-four new stories.

Some of the stories have been edited, and where names are used (unless previously published) they are not the real names of the people involved.

Copies of this book are available online at www.hdc.org.nz

We continue to welcome stories of great care as these are being well received by providers and can make a real difference to how services are provided.

Further stories can be sent to:
Nationwide Health and Disability Advocacy Service
PO Box 1791, Auckland
Free fax 0800 2787 7678
advocacy@hdc.org.nz

For those who prefer to tell their story to an advocate, phone the advocacy service on 0800 555 050 to arrange a time.

Community-based care and support

GENERAL PRACTICE

A doctor who really cares

I am partially sighted.

I am very happy with my doctor, who never forgets this, and waits for me in the reception area, to make sure I have heard her call, and can find my way to her room. She doesn't focus on my disability unless it is relevant to the health issue I am facing right then.

She is able to think ahead when arranging appointments with other health providers, making sure that I will be able to get there easily by public transport, and warning me of potential hazards I may encounter in getting there.

All these things say to me that, although very busy, she has taken the trouble to put herself in my shoes, and to treat me as a whole human being, with courtesy and imagination.

This amazing doctor changed my life

This is a complimentary story about the life changing help and support I have received from my GP.

I am forty-six years old and for probably thirty years have suffered from panic attacks and anxiety. I always believed there was something else wrong with me and that it wasn't stress and anxiety at all. For years I spent hundreds of dollars traipsing around to different specialists for various tests, all of which basically came back okay. I still refused to believe that a panic attack could cause all the symptoms I suffered and continued trotting from one medical centre to another trying to find the answer. I was meanwhile in a dreadful space, still suffering attacks of panic and anxiety, feeling stressed all the time – chasing my tail to find answers and getting no where – UNTIL ...

I decided I needed my own GP. The one I found listened to me and for once in my life I did not feel like an idiot. Fortunately for me, this GP has a particular interest in stress and anxiety. He treated me with respect and a genuine interest in my situation. Although he advised me that certain types of medication would help, I was reluctant to take any pills. Instead of pressuring me to take the medication, he gave me his mobile phone number.

This was to be a safety net for me as I was able to phone him when I had a panic attack. He would talk me through it as he did on numerous occasions and I might add this was at all hours. Not once did he lose his patience with me.

Fortunately for me, this GP has a particular interest in stress and anxiety. He treated me with respect and a genuine interest in my situation

I cannot speak highly enough of this dedicated man who has basically saved my life. I am now able to spend more quality time with my daughter

I spent a lot of time at his surgery in various states of panic convinced I was in the middle of a heart attack or something else life threatening. He and his staff were always amazing and helped me so much.

Eventually I decided that I would try the recommended medication although I was convinced it wouldn't work. Much to my surprise I have never been better in my life. I have always believed I had something far more sinister than panic and anxiety attacks. I have now learned through the patience and understanding of my GP that panic and anxiety is a very serious and nasty disorder and that it can be very hard to treat. I am living proof of that.

I cannot speak highly enough of this dedicated man who has basically saved my life. I am now able to spend more quality time with my daughter and even attended her school camp much to her delight.

I am not sure what else to say, but even if I was to win lotto and gave it to this man, it still wouldn't be enough to show my appreciation and gratitude. He has been amazing in the way he understood and handled my case – giving me back my dignity and my life.*

** This consumer has asked to be a contact for anyone with panic attacks, anxiety and stress. Email: advocacy@hdc.org.nz to make contact with her.*

The kindest most caring GP

My GP is the kindest, most caring doctor I have ever been to. He is always available including evenings and weekends. He even came to see me at 8.30am one Sunday.

I have never been prescribed pills that wouldn't go with other medication.

If in doubt he always checks and consults what I call 'his bible'.

He has chased up doctors at the hospital who weren't responding to requests from him, resulting in appointments.

I had a chronic condition for many years that prevented me from doing lots of things and there was no enjoyment of life. I had many admissions to hospital and my GP was always there for me when I was discharged – often in poor shape.

I would not swap my GP for anyone else's.

COMMUNITY CHEMIST

Great care at a pharmacy

Having fallen in the street injuring my ankle I decided to go to the local pharmacy to buy a support bandage.

Upon my arrival in the store, and seeing I was limping, the pharmacist came over and directed me to a seat. He asked how I had sustained the injury. Upon hearing I had fallen he asked a few pertinent questions about whether I had any other injuries including whether I might have banged my head.

He examined my ankle, comparing it with the uninjured one, checked I could move my toes etc to make sure nothing was broken.

Following the examination he asked whether there was anything in my medical history that would prevent me being able to have certain drugs. Upon learning that there was, he recommended that if Panadol did not relieve the pain that I should see my general practitioner.

COMMUNITY ACCIDENT AND MEDICAL SERVICES

Outstanding accident and medical care

Having dropped a very heavy piece of steel on my foot at work, I knew that I had done some serious damage.

My colleagues transported me to the local accident and medical centre where I was immediately taken to an examination room and the charge nurse removed my shoes and exposed my crushed foot. With great care she made me as comfortable as possible, asked me if I could move my toes and went to find the doctor.

When she returned she apologized about having to cut my jeans as she was sure that I would end up in a plaster cast. Even though they were work jeans the nurse cut them on the inside seam so they could be re-stitched.

The doctor examined me and ordered x-rays which confirmed the broken bones. Both the doctor and the nurse asked if I needed pain relief and explained that they would have to try and clean up the top of the foot as a very large haematoma had formed and the skin was broken.

I was put into a back slab, given crutches and told to return the following day. The next day I was again examined by the same doctor who told me that I had done a lot of tissue damage and crush injuries take a long time to heal. He asked how I had managed at home. I explained that I was having great difficulty using crutches as I had a back problem and arthritis in my hands and I had tripped a couple of times over the past twenty-four hours.

Even though they were work jeans the nurse cut them on the inside seam so they could be re-stitched

The care and consideration displayed by the specialist, and all the staff at the accident and medical centre was outstanding

Without hesitation the nurse suggested that I should see an orthopaedic specialist as a moonboot would make mobility easier. The appointment was made for that afternoon and the moonboot fitted.

A wait and see approach was adopted by the specialist as he did not want to rush into surgery to pin the bones saying that with a history of arthritis it would be better if the bones knitted naturally without surgical intervention.

I continued to visit the clinic every second day to have my foot dressed and at the end of ten weeks was finally discharged.

The care and consideration displayed by the specialist, and all the staff at the accident and medical centre was outstanding and throughout the whole ordeal I was kept fully informed as to what was going to be done and what I could expect the outcome to be.

Within sixteen weeks after the event I was back driving a manual car, working and feeling very grateful for the professional, immediate attention I received when I was first taken to the clinic on the day of my accident.

Great care shown by a radiographer

I had what turned out to be a complex dislocated fracture of my arm. It was very painful and the radiographer showed great compassion at the pain and distress I was in. She took the time to handle me with great care to minimize the pain from the position she needed for the x-rays. Not only did she explain exactly what she was doing and how this would provide helpful information for the doctor to determine an appropriate treatment plan, but she constantly checked I was OK

I really appreciated her caring and professional approach.

COMMUNITY CARE FOR CHRONIC CONDITIONS

I want to tell a good news story about my health care. Treatment has improved so much that nowadays my chronic health condition is easily treated

Praise from a woman who has survived the odds

I want to tell a good news story about my health care. Treatment has improved so much that nowadays my chronic health condition is easily treated. This wasn't the case when I was diagnosed fifty years ago. In those days it was considered serious.

Over those fifty years, I have had superb care from the local health service. There have been the odd personality problems but at seventy-six I am still alive, have seen three children grow up and now have grandchildren to enjoy. Fifty years ago, I was told all that was very unlikely.

Thank you to all those health professionals who have helped me to survive the odds.

Exceptional nursing care

Over the last eight months I have had the pleasure and help of three wonderful nurses, while treating an ulcer on my leg. The nurses were so very thoughtful, not only treating my ulcer but helping an old and sometimes crabby old woman of eighty-seven to see the bright side of things. They have been wonderful and I am very grateful. They were very caring, were always on time and came when they said they would. I was so thrilled to have them provide the care. They sorted out my ulcer when I thought it would never heal. We parted as very good friends.

COMMUNITY ORGANIZATION SUPPORT

Great Care provided by an NGO (non-government organisation)

The Multiple Sclerosis Society provides a range of services for people with MS. An eight-five year old woman who has had MS since the 1950s writes about the quality care she has received from her local society.

Every week for over sixteen years I have attended a session for others like me to get involved in various group activities. This is my only outing and gives me much pleasure. I am not very mobile although after being confined to a wheel chair for fifteen years I now get about by pushing the chair around. I look forward to the happy lively day in a warm room where we are cared for so well. Carers are also welcome and we all have fun, share lots of laughter and I always come away feeling refreshed.

There is a wonderful administrator and a great field officer who helps keep things moving, assisting with serving and feeding when necessary. The cook is a cheerful and caring person who makes great home-made meals catering for all tastes, accommodating late-comers and visitors without any fuss. She reminds me of the 'loaves and fishes' story on some days.

Lots of people show interest in us. As well as the field officer, committee members, student nurses and OT (occupational therapy) trainees pop in to see how we are. Altogether we have a vibrant and caring society.

From strength to strength¹

Fifty-six year old Wiremu loves his flat in Dunedin. "You should see the sun come in, it's beautiful," he says. Wiremu appreciates the freedom of living in the community more than most – he spent many of his younger years in and out of prison.

But for more than a year now, with PACT's support, he has kept out of trouble, made new friends and has started a new life which

1. Wiremu's story was published in full by the PACT Group in Feb 2007. Wiremu was keen to see us also use his story as an example of how great care can make a real difference to someone's life. This is an edited version

*I look forward to
the happy lively
day in a warm room
where we are cared
for so well*

His support worker Te Hau believes his progress is a credit to the holistic approach taken in Maori services where the Tapa Wha model looks at all aspects of people's wellbeing

includes an exercise regime of 5am walks and 6.30am swims every weekday.

Things started turning around for him when he was referred to a Maori Focus Unit in prison and from there to PACT and Te Whare in Dunedin as a RIDCA client. His support worker Te Hau believes his progress is a credit to the holistic approach taken in Maori services where the Tapa Wha model looks at all aspects of people's wellbeing.

Taha Wairu – *Spiritual (mood, energies)*

Every weekday Te Hau and Wiremu do Tinana Whakaoriori, which is a form of karakia and is similar to tai chi. They go somewhere special like St Clair Beach or Vauxhall to do this, so they are in the natural environment.

"It's about enjoying the day for what it is," says Te Hau. "And that's given him a direct connection to Papatuanuku – Mother Earth."

Wiremu says Tinana Whakaoriori is beautiful to do. "It's lovely by the beach in the early hours of the morning by the sea."

Taha Tinana – *Physical (diet, exercise, body)*

Te Hau and Wiremu began to walk every day while he was still at Te Whare. For more than a year now Te Hau has picked Wiremu up at 4.50am every weekday and by 5am they're walking around South Dunedin and then off to the physio pool for a swim.

Te Hau doesn't think there's anything special about her getting up at that hour each weekday. If I'm preaching that you've got to be healthy to live longer then I've got to practice it myself and it's got to be good for me as well."

In the evening, another walk. Wiremu's diet has also improved and his diabetes is now under control. He says he didn't even know he had diabetes until it was picked up on one of his stints in prison.

Taha Hinengaro – *Mind (thoughts)*

Te Hau says Wiremu's thinking is now sharper. She and Wiremu often talk about keeping safe in the community. "In reality I can't be with him 24 hours a day so he needs to put some strategies in place and that's when I talk about the sharpness of his mind. He's very good at knowing how to put those into place."

Wiremu knows now he can just walk away from situations that in the past got him into trouble.

For the first time in his life he has all his bills sorted out. "I'm so proud," he says. He is also joining a literacy programme. Te Hau describes the changes she's seen in Wiremu as amazing. "He's now back in the community and everything he has in his house he owns."

Taha Whanau – *Family (relationships, social environment)*

Using the Te Pa Harakeke (the flax bush) framework which is about

It's about him and who he is as a person. He's got great determination that he can do it with support and guidance

roles and responsibilities within a whanau, Te Hau looked at where Wiremu sat within his family.

“Because he was the tuakana (the oldest), he had some special unique roles that he needed to play and one of them was whakapapa, genealogy – knowledge of whakapapa and who he passed that down to because he has no children. His ancestors have given him that knowledge and for him to pass it on to his siblings.

Te Hau says it makes him feel good to know that there's whanau who still love him. Wiremu also likes having a new circle of friends around him. He says his neighbours are lovely and have been very generous.

He's found openness with many Dunedin people and has been open back himself.

“I say ‘I came out of prison and I got sent down here.’ They never even asked ‘what were you in for?’ They just said ‘How do you like it down here?’ I say ‘it's beautiful’.”

“The people are so friendly. I think I found a new place and a new life.” Wiremu says he had never done things like the exercise he and Te Hau now do before. “I'm very glad they sent me down here.

He says Te Hau made him think hard. She always tells me – think about what you do, before you start.” He says PACT has really helped show him how to make positive changes.

Te Hau says Wiremu is on a journey of his own. “It's about him and who he is as a person. He's got great determination that he can do it with support and guidance.”

STORIES FROM VOLUNTEERS ABOUT THE JOY OF PROVIDING GREAT CARE

Affirmation of our work

I was helping an elderly client at the ATM recently. It was freezing cold and right in the path of a wind tunnel. My client simply wanted some cash, but before doing so had to transfer some money from one account to another. However, all this takes time as it involves getting an account balance from one account, then getting the balance from the other account, then having a think to decide how much to transfer, before actually transferring the money and then finally getting out the cash. Throughout the process constant explanations were needed to assist my client.

The whole process probably took us about five – six minutes (although it seemed longer,) and through all this time there was a middle aged guy standing patiently behind us watching me assist my client through the mysteries of the ATM process. When we had finished he said to me, “Gosh you are so patient, that was just lovely to watch”.

It made my day!! I think we sometimes get so wrapped up in what we are doing that we forget to stop and think about how well we go about our work.

From a WesleyCare Volunteer

The joys of working with older people

I found myself wading my way through the dizzying array of options of voluntary work on offer in the Wellington region.

I had privately resolved myself to making a commitment to doing some form of activity on a regular basis now that home renovations, arrival of a first child, career commitments and every other supposed time limitation was either under control, or better managed.

So, what to do? I always had a desire to help the elderly, so it was to the Wesley Care Team that I gravitated. Apart from a desire to help and the satisfaction gained from being there for someone, I also had some reservations about whether we would get on with each other and what if they had a big Rottweiler dog in the front yard?

Soon after the initial interview and training session I was offered a gentleman by the name of 'Jack' to visit. I was briefed that he was a fit, sprightly ninety-seven year old with a sense of humour.

Upon my first meeting with 'Jack,' all my initial concerns were allayed.

'Jack' is near sighted and partially deaf. He is remarkably mobile for his age and does press-ups on the side of his chair. 'Jack' loves to greet and farewell me by shaking my hand very, very firmly to show his strength which in turn puts my generation's greeting gestures to shame.

'Jack' also possesses an incredible memory for dates and numeracy. Several times he has repeated statistics highlighting a better recall than I have at the relatively tender age of thirty-six.

The most memorable times I have had from my Sunday visits with 'Jack' are the stories that he tells from life as it was early in the Twentieth Century. Having emigrated from Britain before World War 1 as a child, his recollections of New Zealand, (especially the West Coast mining towns) are truly amazing.

I myself gain a level of personal fitness through mountain biking and running, but people of 'Jack's' generation were very different.

When I'm tired and I need to heat my dinner in a microwave, I think of Jack's large family having cold baths in winter, and trying to light the coal range.

It's amazing to think people still walk among us that were considered 'too old' to join the Expeditionary Forces in World War 2.

The most memorable times I have had from my Sunday visits with 'Jack' are the stories that he tells from life as it was early in the 20th Century

These stories are all the more poignant and visceral when being told first hand. The infant mortality, dangerous driving conditions, two room housing, Japanese prisoners of war in Featherston are sometimes sad, and sometimes laugh out loud fun, but always fascinating.

I think that my initial thoughts of 'being there for someone', were really a bit naïve. In reality, I am fortunate to spend the time learning and listening, and in return, I occasionally plane down a door or two if they stick, or dampen a wildly swinging rocking chair in payment to hear these fantastic yarns. They don't even need embellishing!

On top of all this, being a fan of film festival movies, 'Jack' is educating me (inadvertently!) on the history of cinema via his Sky TV package, so Clark Gable, Fred Astaire, Betty Davis and team are back-filling my cinematic experience.

Thanks for the memories 'Jack!'

Full version published in the WesleyCare Volunteer Voice Newsletter Wellington. April 2007

Disability services and independent living

NEEDS ASSESSMENT, SUPPORT AND EQUIPMENT

Help and equipment tailored to our needs

I would like to say how much help my husband and I have received from the local health and disability service.

When I had a hip replacement eighteen months ago I was supplied with several pieces of equipment to aid my recovery. I also received follow-up care.

More recently my husband, who suffers from Parkinson's Disease, has also had tremendous help that has made such a difference. The equipment supplied to him includes bed handles and a monkey pole, walker, toilet seat and trolley plus a base for his arm chair.

He has received visits from the physiotherapist and occupational therapist, who are coming again to advise on a wheel chair. The district nurse comes to check on him weekly as he now has a self retaining catheter. Care givers come to shower him daily.

A lady from the needs assessment and service co-ordination has visited to assess our needs and I am allowed twenty days carer support.

I was really struggling to cope with the situation and without all this

I would like to say how much help my husband and I have received from the local health and disability service

help don't know how I would have managed. I am truly grateful to all the wonderful people who have done so much for us.

RESIDENTIAL FACILITIES

Respect for parents as experts in their own child's care

There was one absolutely 'stand out' moment when attention and care from all concerned was just perfect

Despite all the frequent difficulties we have experienced in our multiple calls on the health and disability system over the years, there was one absolutely 'stand out' moment when attention and care from all concerned was just perfect. Here's a quick summary:

Our son has a significant metabolic disease, a very rare one, and there was little NZ knowledge about symptoms, management, prognosis, etc. It transpired later that at the time there was only one other patient in NZ with this condition. Our own enquiries took us to conferences overseas and put us in contact with medical specialists who knew the condition and scientists doing basic research on the condition, so we were very well informed, despite not being health professionals.

Of course this sort of family expertise can provide quite a challenge to health professionals, and it is not always welcome.

Our son started displaying unusual symptoms quite suddenly. He was confused, disoriented, upset, and had difficulty talking. We knew that when this had occurred for other patients with this condition there was great concern that this may be the beginning of neurological degeneration that is common to many of these rare diseases, and possibly the beginning of the end. Apparently it had often been treated as this.

We knew differently. Despite no published articles on this behaviour for these patients, we were aware that several had been through this sort of experience then returned to their usual equilibrium. The symptoms were retrospectively understood to be signs of classic psychosis, usually triggered by some identifiable stressor.

Instead of contemplating neurological tests and preparing for possible decline of functioning and palliative care, the appropriate course of action was to treat with an anti-psychotic.

I took our son to the GP and he accepted my advice immediately and wrote a prescription as per my suggestion. The GP had accepted my expertise on this condition.

Our son did not respond well to the medication and had significant side effects. We were referred to a consultant at the specialist rehabilitation centre who had previously assessed his physical health. He actually made a house call!!!!!!!!!!!!!! Again my advice was accepted and factored into the treatment decisions. The medication was changed and titrated and our son recovered quite well from this episode.

They worked wonderfully well to get him through the episode and the support agency did not quibble about the extra staffing needed for a number of weeks

Other families told me that when their child went into this state they went through hell because they and their doctors had no knowledge that it was a psychotic episode and all had feared the worst.

Our son lived in supported housing and the staff needed to put a special regime of close care and support in place. They did not question or challenge our judgment. They worked wonderfully well to get him through the episode and the support agency did not quibble about the extra staffing needed for a number of weeks.

Despite the whole scenario being more difficult to deal with than any physical health problem, we got through without the grief and panic that others felt. Having our knowledge and expertise accepted by the health professionals made such an incredible difference.

What could have been an absolute nightmare for us, was just tough and stressful, as would be expected in the best scenario for a first psychotic episode.

We have since contributed our experience as a case study in an academic paper.

There is now a better understood link between metabolic disease and some real risk of psychosis, as well as identification of presumed psychiatric illness that is better explained by underlying metabolic disease that may not be diagnosed.

Win, win all round in our case.

Support and encouragement to achieve a great life

When our son William was born with spina bifida and other impairments, he was given months not years to live. He is now approaching his fiftieth birthday. For the first twenty odd years of his life he lived at home in a provincial town with his five sisters and went to our local schools. Although in a wheelchair he was accepted and included in all aspects of schooling. Although not very academically inclined, he learnt a lot orally and through experience.

When he left school at fifteen years he traveled daily by bus to attend a CCS workshop. Over the next five years or so the bus service was cut back and then stopped altogether. After much searching we were unable to find anywhere suitable for William to live locally with a wheelchair so he could continue attending CCS. At this time a placement came up at a residential facility in a large city centre. This proved to be a great opportunity. Living in a small town there was nothing much for William to do. He settled well at this home and was given a permanent placing which has turned out great for him and us as his family.

Over the twenty plus years he has been there, it has been an ongoing learning curve. It is now his home and the residents and

The home provides him with security as well as the freedom to attend outside activities.

staff are his second family. He has developed both socially and to a degree academically. He gets great pleasure from his computer which he receives ongoing help with and is able to keep in touch with his sisters in NZ and Australia.

He gets enjoyment from music and interaction with the other residents in all manner of activities such as drama, photography, gardening and being on the resident's committee. He is very involved with his church. The home provides him with security as well as the freedom to attend outside activities. This has allowed William to develop in many ways which would have been impossible without the support and encouragement he has received there.

SUPPORTED COMMUNITY LIVING

Care that promotes independence and helps people help themselves

Monica's story is one of freedom, from being institutionalised for over 50 years and now finally having her own unit to live in where she feels safe and secure. She can make her own decisions, care for herself with a little assistance and enjoy the luxury of grocery shopping, watching television, preparing her own meals and planning each day.

Although her home belongs to a disability organisation it is a stand alone town house and not attached to the residential care facilities.

Monica's life has been that of a battler, fighting for her rights as an individual. She fought to have her own place as it has provided her with dignity and respect and she can care for herself and maintain the privacy that she values so much. She has sustained years of physical abuse in various institutions and to never have to worry about such things happening to her again has given her great peace of mind.

Monica's evening meals are cooked by her caregiver and she is taken out once a week to do her grocery shopping. She enjoys having the freedom to choose what food to purchase and plans her meals one week in advance. Sometimes she purchases frozen meals so that she can exercise independence by microwaving her own evening meal. Being supported to live like this is real freedom compared to the many institutions she has lived in over the years, where meal times were regimented, there was no choice in the food provided and privacy and safety were difficult to achieve.

To have the choice of when she wishes to watch TV and what she wants to watch is an absolute luxury that she has never had the opportunity to enjoy previously. As Monica says, "it is the normal everyday things that normal people do that I am now enjoying so much".

Being supported to live like this is real freedom compared to the many institutions she has lived in over the years

She does all her own laundry and attends to all her personal cares. She said that it is a much better place where she is now living and the caregivers are very kind to her. Her caregiver assisted her to change doctors and she is very happy with her new GP.

Safety is very important to Monica. She wears a St John's medical alarm as protection. She has a number of medical conditions and having the alarm gives her a sense of security knowing that if she is unable to get to a telephone to summon help she can just press the button and St John's will respond.

Monica wrote the following on her Care Plan of what she would like her future to be like.

- I want to be looked upon as a normal person and not treated as though I have a psychiatric and intellectual disability
- I want to be involved in activities in the community
- I want to continue with my voluntary work
- I want to maintain my essential rights such as attending legal and medical appointments when I need to
- I need to continue my friendships which are extremely important to me and to continue to socialise because that is how new friends are made

I want my home to be where:

- I feel secure and safe
- I have wonderful caregivers who treat me as though I am their own family member and where I am supported to become more independent

Great support to have a great life

I am an adult woman with an intellectual disability. Some days I go to the day service at IDEA Services, where I can chat to my friends and get involved in other activities. The staff and other people there are a great support to me.

I have my own unit and live by myself near the local beach. I like to go for a walk down to the beach and I do my own shopping at the supermarket. I can go on the buses to other places and catch the bus by myself to the library to get 'talking books' out.

I like to be independent and do my own cleaning in my unit. I also do my own cooking and sometimes I do baking. I like doing puzzles and listening to nice music.

I like to help people. I have got nice neighbours. When they go away I feed their cat, water their garden and bring the mail in for them.

I like helping my sister; I am a good help to her. I help my sister to move things. I said to her "we girls can do anything".

Some days I go to the day service at IDEA Services, where I can chat to my friends and get involved in other activities. The staff and other people there are a great support to me

Hospital services

EMERGENCY CARE

All of the health professionals – nurses and doctors – that we came in contact with during our stay in hospital were caring, sensitive to our needs, communicated clearly, and most importantly treated my daughter respectfully

The small things made all the difference

Recently my daughter had to have an emergency operation to remove her appendix. We arrived at the accident and emergency department at about 6am on a Monday morning. She was in severe pain and could hardly walk. She was seen almost immediately, very quickly assessed and appendicitis tentatively diagnosed. By 10.30am that morning she was in theatre being prepped for an operation to remove her appendix. As the appendix had burst she ended up needing to stay in hospital for four days. All of the health professionals – nurses and doctors – that we came in contact with during our stay in hospital were caring, sensitive to our needs, communicated clearly, and most importantly treated my daughter respectfully. A specific example, although small was significant for my daughter. When we knew she was going to have to go to theatre she was told she would have to take off all her clothes and put on the theatre gown. She was very shy about having to remove her underwear so the nurse told her it was OK for her to leave them on. If she was made to take them off she would have been very conscious of this the whole time and would not have relaxed.

Another example was being offered her appendix to dispose of in a way appropriate to us. Although we didn't take up the offer I was impressed that the offer was made.

My daughter has a beautiful, but for some people, quite hard to pronounce name. Even though not everyone got it 100 percent right everyone made the effort and if they weren't sure they asked. Simple stuff!

Overall I was thoroughly impressed with the care given not only to my daughter but also how our whole family was treated during this time.

Busy yet still caring and attentive

Periodically the media tells us horror stories about patients visiting hospital emergency departments. We have nothing but praise after our recent experience.

I took my twelve year old daughter to the after hours medical centre as she had a high fever and headaches. She was referred to the emergency department at the local hospital as there was concern with some of her symptoms.

Every staff member she came into contact with was fantastic. Caring and attentive even though they were busy they even managed to crack a few jokes which took her mind off her illness. We had to wait

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The hospital had a fantastic follow-up procedure. Each day we were phoned by an amazing nurse, from the children's unit who checked on my daughter's progress.

a couple of hours to be seen but nurses kept checking her during this time and reassured us.

In particular we have to praise the paediatric registrar, who was not only thorough and caring, and phoned us the next day, but also had the most outstanding bedside manner of almost any doctor I have ever come into contact with. We wish all doctors could learn from him.

The hospital had a fantastic follow-up procedure. Each day we were phoned by an amazing nurse, from the children's unit who checked on my daughter's progress. She was also able to give advice and answer my queries.

We were so impressed with our local hospital for providing consistently great care during a stressful time.

Emergency department professionalism of the highest order

My GP referred me to the local hospital emergency department for acute abdominal/back pain that in her opinion required emergency specialist assessment.

Having heard a lot of negative reports in the media about emergency departments, I wanted to tell you about my experience. From the efficient ED receptionists to the quiet precision and friendly professionalism of the nurses, the surgical registrar, the radiographer, and even the parking booth attendants (kindly checking whether we intended to return, presumably to ensure that we could reuse our parking ticket), I was enormously impressed not only with what appeared to be excellent technical skills in their respective fields, but also a genuine respect for the patient expressed in an open and communicative manner.

I observed professionalism of the highest order at every stage of my treatment.

I recognised that my own needs were less urgent than some other patients, and was happy to wait from time to time; yet this was not so much due to any particular altruism inherent in my own character, as to the actions of staff themselves.

For example, medical staff regularly communicated what to expect so at all stages I knew what was happening, how long it would take and why. I was treated with respect, and was therefore able to understand the triage, assessment and treatment decisions, as well as the waiting times.

I was happy to wait because it was clear that my own treatment was being handled efficiently, as evident in the actions I observed and my communications with staff. For example, "it will take about an hour and a half to get blood test results, so let's take the blood

now.” And later, “we’ll now arrange for the X-ray, so the slides will be ready when the doctor is free to see you again”, etc. This full and open communication, along with the evident efficiency, of the DHB staff left me feeling entirely happy with my treatment throughout.

In conclusion, although it is clearly vital for medical staff, and indeed all professionals, to have the requisite technical skills to competently perform their duties, the staff I was privileged to come into contact with in ED displayed an equally vital component of true professionalism. These included genuine respect and empathy as well as open and frank communication with patients.

Sensitivity and human care made a big difference

Driving to the local hospital’s emergency department on a sunny spring Sunday morning is not ideal and as we neared the entrance I turned to my husband and exclaimed quietly that I really didn’t feel like any more pain and indignity.

Having already endured the journey leading up to the need for a hysterectomy, interspersed with a kidney stone attack, a torn back muscle and carpal tunnel surgery, pain and loss of dignity had become all too familiar.

So ten days after the hysterectomy, to suddenly be faced with post-operative bleeding was a disappointment. After spending an hour sitting behind three young men whose joint body odour could have almost left me inebriated, I was called into the treatment area by a smiling young doctor who immediately introduced herself and apologised for the wait.

From the beginning her warm and relaxed manner guaranteed I was in caring and capable hands. Her delightful but appropriate sense of humour was infectious yet when needed, she provided me with clear and easy-to-understand information. Her physical examinations were gentle but thorough and even the taking of blood was easy.

To experience this level of clinical care coupled with human care was just so welcome for me, who at this stage was so tired of dealing with pain, discomfort and being intimately explored. This doctor will probably never realise what a difference she made in my journey to recovery but she is a true example of how good care looks.

From the beginning her warm and relaxed manner guaranteed I was in caring and capable hands

CARDIAC CARE

Nurses that really cared

Following cardiac surgery I had the good fortune of recuperating in a hospital with great nurses that made me feel more like I was at the ‘Holiday Inn’. My two weeks stay with them really put me back on my feet.

I found the nurses on the cardiac ward to be utterly professional as well as very friendly and caring. After the surgery I had to go back there to get my leg dressed and it was a bit like 'coming home' as everyone was so interested in what had been happening to me and how I was.

A doctor experiences great care as a patient

My patient journey began with some slight chest tightness when pushing the mountain bike hard. With the likely 'angina' I went to my GP with the question – should I train lighter or harder (to open up alternative collateral blood circulation to the heart)?

He wisely did not become suckered in to answering this question but referred me to the local hospital where the physician carried out a stress ECG test on a treadmill. He did not like what he saw on the ECG, aborted the test early and referred me to a cardiologist at another DHB who carried out an angiogram.

This showed a seventy-five percent restriction of the left main stem that supplies two thirds of the heart muscle and I was confined in the hospital as an inpatient. After one postponement, due to a lack of available intensive care beds, I was given a double coronary graft.

As I was informed of a two percent mortality 'on the table' or shortly thereafter, my mind was focussed and somewhat contemplative.

The odds of winning Powerball at 1:20 million become a lot more attractive and I brought a ticket. Fortunately I woke up after the operation but did not win Powerball – but I was happy.

The healthcare provided was of the highest quality and was exemplified by

- Courteous, caring and effective staff
- All referrals for specialist input or diagnostics (radiology and laboratory) being acknowledged within twenty-four hours (mostly within twelve hours)
- Flawless transition between primary (GP/community care) and secondary (hospital/specialist care) and back again

Wonderful care

I am eighty-four years old and have been to hospital several times where I recently received a pacemaker. I have found the care to be wonderful especially from a particular registered nurse who works tirelessly for the patients. I am so grateful for every effort made.

*Flawless transition
between primary
(GP/community
care) and secondary
(hospital/specialist
care) and back again*

A transparent and caring service

As a long term sufferer of a serious bowel disorder, Ava had received private care for many years. When she was unable to keep up her medical insurance, she was referred to the local hospital for ongoing surveillance.

After a crisis with the hospital referral system where she along with others slipped through the cracks, she received an outpatient appointment to see a surgeon. At this appointment she was told she would need a colonoscopy and was given an estimate of when this would be likely to take place.

She received a telephone call from a staff member at the hospital managing the waiting lists and surgical appointments for those who needed endoscopy care at exactly the time she had been told to expect a call. She was given a time for her procedure and received written instructions in the mail the following day.

On arriving at the theatre suite, she was greeted by two nurses who carried out pre-op checks and explained the procedure. Ava expressed concern that the last time she had this procedure she had experienced a high level of pain and was afraid the pain might not be adequately managed today.

This information was passed on to the theatre staff and the surgeon gave instructions that the pain medication was to be increased when Ava indicated she needed it.

Following the procedure the surgeon came to the recovery room and told Ava he was pleased with the examination, to carry on with the same medication and that he would see her again in three years.

Ava had her blood pressure taken and other checks to make sure she was making a good recovery. She was given sandwiches and a cup of tea and then escorted to reception where her brother was waiting for her. Exactly two and a half hours after arriving at the hospital, Ava was back at home drinking yet another cup of tea!

She described having received a wonderful service, carried out by caring, competent personnel who kept her informed and bent over backwards to make the whole process as streamlined and stress free as a colonoscopy can ever be.

Great care that put me at ease

When I arrived at the out-patients clinic at the local public hospital the bright caring nature of the staff was very welcoming. The professional and thorough treatment by the attending specialist made

Exactly two and a half hours after arriving at the hospital, Ava was back at home drinking yet another cup of tea!

If we can take responsibility for our own health or get an advocate to speak about our needs on our behalf, it can really help when this is so well received by the staff

for a very relaxing trip to the hospital and any anxious feelings I had before I went, quickly dissipated.

Again the following day when I was admitted for day surgery, I was welcomed with smiling faces and excellent treatment by all staff I came in contact with.

I must say I appreciate the way everything went on those two days and felt much better for it.

Responding to my needs resulted in great care

I received great health care when I had a procedure at a large public hospital. One of the reasons it was such a positive 'outcome' was how well informed and prepared I was. I was communicative and enquiring of all members of the team, including the anaesthetist and the clerk. I also asked my GP to write a letter that expressed clearly what I wanted to happen and describing what supplements I took. The staff responded well to my proactive efforts to be involved in my care and to be well informed and were very attentive to me.

If we can take responsibility for our own health or get an advocate to speak about our needs on our behalf, it can really help when this is so well received by the staff.

A patient-centred journey

A woman in her eighties has an outpatient appointment prior to having a hip replacement.

She is unable to walk unassisted but volunteers quickly appear with a wheelchair and take her straight to the clinic, check her in and wait with her while her support person parks the car. They introduce her to the clinic receptionist who is happy to help if she has any concerns and points out the prominent notice which asks patients to let the receptionist know if they would rather not have someone in training involved with their care.

A nurse quickly appears, introduces herself and provides contact details. She states she will be the contact person as her role is to coordinate all aspects of the care until discharge from hospital following the surgery.

She takes the woman and her support person to a room next door where a house officer checks her physical condition. The house officer is concerned about her heart being enlarged and arranges for the anaesthetist to call in to the clinic to assess the situation himself and explain the anaesthetic options to her.

In the meantime, the house officer explains that an x-ray is needed to have a better idea of the condition of her heart. The x-ray is carried out within the same clinic.

After the x-ray has been taken the woman goes to the room next door where a lab technician takes a blood test and hands her a container for a urine sample. To avoid the indignity of having to walk down the corridor holding a urine specimen there is a cubby hole in the toilet for patients to place it where the lab technician collects it from the other side.

It is now time to meet the surgeon and discuss the operation before the anaesthetist arrives. The entire preparation for the surgery has taken place in one facility and without undue delay. The woman feels well informed and confident about the operation and those who will be caring for her.

HOSPITAL TEAM CARE

Quality care provided by teams that work together for patients

I became acutely ill and was admitted to a large public hospital with the symptoms of an acute infection. I was allocated a bed and seen within the hour by the medical registrar. It was very difficult to diagnose my condition as I have an autoimmune condition which suppresses physical signs of infection even though my blood results showed a severe infection.

I was seen by a physician, the infectious disease consultant, the rheumatology consultant, the orthopedic consultant and the medical team. The good communication between these teams resulted in my receiving excellent care throughout my stay of several weeks in the hospital. The nursing staff were professional and provided expert care. The physiotherapists, lab staff, radiology staff, orderlies, kitchen staff and cleaners all treated me with respect and provided as much privacy as was possible within a four-bedded room. I received good information about procedures from the person involved prior to receiving treatment.

I was impressed at the quality of staff employed. They were all very cheerful in spite of dealing with some challenging situations amongst my fellow patients.

I am continuing to recuperate from my illness. I have had several setbacks and attend outpatient appointments each month. I am cared for by district nurses and physiotherapists. It has been a long and hard road for me and the journey has been made easier by the high quality of care that I have received.

I am saddened by all the negative media stories about the public health system as my experience was mostly positive. I wish to support you in telling the positive stories to the public of NZ and I congratulate you on taking the initiative to do so.

The good communication between these teams resulted in my receiving excellent care throughout my stay of several weeks in the hospital

A letter of thanks to the team that really cared

I would like to take this opportunity to say thanks to everyone who was involved in my care and recovery during my recent stay in hospital.

To the tall young male doctor who saw me first; thanks for diagnosing my gallbladder but especially thanks for the morning after the operation when you looked in my eyes and smiled and we shared a joke about the hospital's rubbery cheese.

Thanks to the surgeon who performed the successful operation but especially for the night of the operation when you took the time to sit on the end of my bed and explain what you were going to do.

Thanks to the many nurses who made sure I received my antibiotics when they were due but especially thanks to those who administered the drip slowly and flushed my line gently. Thanks to the nurses who gave me panadol when I needed it but especially thanks to those who rinsed a face cloth under cold water and put it on my very hot forehead and additionally thanks to the nurse with the cold hands who 'touched' my burning forehead.

Thanks to the doctor who came on day three to explain the delay in my surgery and the care taken in my diagnosis but especially thanks for that morning when you acknowledged my pain by touching your hand on my leg as you left.

Thanks to the nurses who were there when no one else was as I shared my tears.

Great care in a private hospital

These collective comments from over fifty patients highlight the features of great care that made a very real difference for them at this hospital. These have been used to identify common themes and key areas. Some individual comments are also included.

Attentive and caring staff

Many praised the nurses, describing them as fantastic, bright and happy and excellent for nervous people in particular. Other comments included:

- Not only acknowledging people's fears, but also putting them at ease
- As a retired nurse I was particularly impressed by the professionalism of the nursing staff who cared for me.
- Keep up the friendliness of nurses to patients as I felt like I wasn't just a 'number'
- I would like to thank the nurses for their great job of looking after me as they were very good at patient care

Keep up the friendliness of nurses to patients as I felt like I wasn't just a 'number'

Receiving care from staff who were efficient, compassionate, good humoured, positive, reassuring and empathetic with an air of relaxed efficiency

Other qualities in the staff that patients valued when using this service included

- Being showed respect and patience
- Feeling like my dignity was always looked after
- Receiving care from staff who were efficient, compassionate, good humoured, positive, reassuring and empathetic with an air of relaxed efficiency
- Being cared for by very pleasant and obliging staff where nothing was ever a problem for them and no request big or small was made to be an issue
- Skilled staff who also show a love of the job and caring for people

Exceptional Care

As well as being treated compassionately and with respect, the patients valued the high standard of both the nursing and medical care including the equipment used and follow up care provided.

- The medical care was first class and provided in a most relaxed manner
- Top quality service and standard of care from a top quality facility
- A courteous and professional service
- Care of my daughter while having surgery and after was exceptional
- Outstanding care, would come back if I have to!
- I would recommend this hospital to anyone

Positive Patient-Centred Environment

Patients also appreciated the ease of the admission and discharge procedures and that there was no waiting around. They were met at reception and made to feel welcome and appreciated the warm and friendly fuss-free atmosphere. A number of them said they felt safe. Parents commented on the child-friendly environment where it was easy for them to stay over with their children.

- I liked the total care package, not only for the patient but for the family as well
- Hospitals can be daunting but this one was brilliant
- Excellent system for young children
- As a parent staying over I felt very welcome

People also commented on the quiet, calm, peaceful and restful surroundings as well as the standard of cleanliness and quality of the food.

- I appreciated the clean uncluttered areas I had to use in my short visit

I liked the total care package, not only for the patient but for the family as well

The meal after my surgery was superb. Please thank the chef for the fabulous, fresh, hot food

- The meal after my surgery was superb. Please thank the chef for the fabulous, fresh, hot food
- I had a really lovely stay on my fortieth birthday

Well Managed

A number of people noted the role of the management in supporting the nursing and medical staff to do a good job and achieve job satisfaction. The comments included:

- This is the best managed hospital I have been in
- Congratulations to the hospital manager on running such a great hospital
- Best run nicest hospital I have ever been in
- To the Captain of this ship – I have sailed with you for fourteen years. Thank you to you and your crew for all the safe voyages

Maternity services

Wonderful midwifery and public hospital care

We are writing about the wonderful care that we received both during my pregnancy and also on the birth of our daughter at a large public hospital.

We picked a midwife to be our LMC (lead maternity carer). We were very lucky to have received a recommendation to use her, and we simply could not have been more pleased with the care we received from her. We felt that at all time we were in 'no-nonsense', experienced hands and that we were receiving excellent and well-balanced advice. Our midwife has a fantastic approach, both personable and direct, so appointments with her were always both a pleasure and a reassurance.

When it became clear that our baby was in a breech position and would need to be delivered by caesarean section, our midwife gave us sound guidance on the public hospital system.

We had concerns about whether or not to pay privately for a specialist at that stage, but she encouraged us to put our faith in the public hospital team. She came to the hospital on the day and was present to support us before, after and even during the operation.

She also visited every day we were in the hospital, although there were no complications and everything was going very smoothly. As she has a busy schedule this support was much more than we had expected. It meant a great deal to us to have our own midwife, whom we had got to know and trust, on hand throughout the birth and those first few days.

The anaesthetist did a great job at keeping us both relaxed and relatively jovial during the operation – we were very impressed with his manner

We were fortunate to have had an excellent anaesthetist and a very experienced specialist who conducted the caesarean section. We are also very thankful to them both for making it all relatively easy. We felt entirely safe during the operation and my recovery has gone considerably better than we had expected. The anaesthetist did a great job at keeping us both relaxed and relatively jovial during the operation – we were very impressed with his manner.

The assistance, kindness and encouragement of the hospital midwives involved in looking after us for the first couple of days helped us get off to the best possible start.

As you can see, we cannot speak highly enough of the midwifery and hospital care that we received. It seemed to us to be a very good example of the public health system working as it should. As nervous first-time parents, we had initially looked at paying for private maternity care, but in fact our experience seems to have rated better than that of many of our friends who have paid for specialist LMCs.

One of the main reasons we feel compelled to tell our story is that we have read a great deal of negative publicity in the media over the years about the public health system, so we were astounded by how different it turned out to be for us. Thank you very much!

Fantastic care from a fantastic team

Thank you to the midwifery team for the wonderful care and support throughout my pregnancy, the birth and postnatal care of our gorgeous little boy.

I had numerous complications during my previous pregnancy and the trauma of this, the hospitalization and the stress of dealing with two premature babies led to postnatal depression. This next pregnancy raised lots of difficult emotional issues for me and I struggled to deal with being so far from medical facilities and finding a midwife I felt confident would enable me to have a birth as natural as possible while being highly alert and responsive to the possibility of complications.

I feel extremely fortunate in finding not one but three such midwives. From our very first conversation, I felt they listened to my concerns and were empathetic. I grew to have confidence in their assurances and appreciated their willingness to support the process I needed to go through to get to the point where I could be comfortable with a natural birth and regain confidence in my ability to breast-feed and care for a new baby.

They communicated so well as a team that I never felt disadvantaged by having three people involved in my care, or by being in a rural environment. In fact I saw lots of evidence of the strong network of relationships they have all established over the years, with other professionals who support and enhance their practice.

The birth and our stay afterwards at the rural health centre went better than we could have hoped for. The care and effort put into creating a facility that is family and baby-centred has resulted in an environment that all of our visitors commented on. We felt it was a critical factor in the success of our start to life with a new baby.

Over the next few days, as we came to terms with our new baby, it was reassuring to know that the midwife, nurses, and our community psychiatric nurse were close at hand. We appreciated the privacy and freedom that the centre afforded us as well as its suitability for juggling the various requirements of toddler siblings, breast-feeding complications, visitors, getting sleep, and managing an unsettled baby – not to mention stitches, breast pumps and the need for privacy, reassurance and advice as needed.

We would also like to pass on the gratitude and appreciation of my parents, who had had some reservations about a rural delivery but were completely overwhelmed by how empowering and humanising the environment was, and by the unexpected but warm welcome they received from the night nurse, at 2am after a four hour drive through the night.

I loved the food, the spa bath was pure luxury, and I would never want to go through another post-birth experience without having the midwives at hand and my husband able to stay in and support me in the days following the delivery. I would forgo the benefits of an epidural any day for such an overwhelmingly positive birth experience.

Supernova: an inspiring midwife

Many many stars shine in the ‘midwife sky’, I thank them all. But for me one star outshines them all – my midwife Becky.

From the start she inspired confidence. It was my first pregnancy and I really wanted a home birth. I thought it beyond me because of my family history and rural location. My first meeting with Becky saw me emerge confident in my ability to birth safely at home. That same appointment was inspiring as I realised that birth was something not to endure as a means to an end, but something special to experience. I emerged inspired and excited from that meeting. I knew I had chosen the right woman to share my special journey with.

Since that first meeting some years ago, Becky has welcomed both my children into this world. We were fortunate to have two peaceful home births which happened in a most perfect and natural way – a healthy woman giving birth to a healthy child at home. My husband supported me along with two skilled professionals. I was able to lead the way in my own space and time. Becky was always available but never intrusive. Intuitive and strong, she knew how to handle

That same appointment was inspiring as I realised that birth was something not to endure as a means to an end, but something special to experience

me when I didn't know how to handle myself. My children had a beautiful and gentle start to life outside the womb, and I was left feeling beautiful, strong and incredibly clever.

People thought I was brave to give birth at home – but is it brave if there is no fear in the first place? It was made clear to me that women still die in childbirth yet I went into my births with informed confidence. The relationship I had built with my midwife during the pregnancy gave me confidence knowing that her values were aligned to mine. I knew she would speak and act for me if the situation arose where I could not. I knew Becky had my wellbeing and that of my child at heart. I had faith in her competence and judgement. She would not put either of us at risk.

Although Becky has caught a large number of babies, I felt that my births were incredibly special, and my babies truly amazing. I was able to share my awe and wonder with a woman who appreciates that miracle babies are not limited to those who bravely battle illness and circumstances to survive. Every new life is a miracle and every child is a gift.

Becky is mother and child focused. She thinks outside the square, doing what ever needs to be done to ensure an optimum pregnancy and birth experience for both mother and child. The quality of her care is not dependent on the quantity of her funding. Living in the country meant greater travel costs and time for her but she never seemed to begrudge this. She just gives. She is there to support the mother and child, it's not about her. She's not interested in impressing anyone; she just skillfully does what needs to be done.

Caring for a mother and child includes acknowledging the role of the wider whanau with sensitivity. Becky quickly won the respect of my parents.

Nothing prepares us for parenthood, except parenthood. The reality is sometimes parenting is hard however you do it. Our whole family culture continues to benefit from the example and encouragement of the midwifery care we received.

We don't know how lucky we are here in New Zealand. We are lucky that a midwife's role is not just about birth, but includes the relationship right through pregnancy and following birth. I loved being pregnant and becoming a mother but it was still an emotional journey. Although my body was able to handle pregnancy and birth on its own, my heart and emotions took a little longer to catch up. Becky nurtured the wellbeing of my soul as well as my body. Not only did she share her own wisdom and strength with me, but she empowered me to find my own. Her depth is balanced with fun and laughter.

Midwifery is not a separate part of Becky's life. Midwifery is simply a part of who she is. Her integrity and passion for life is carried through

Midwifery is not a separate part of Becky's life. Midwifery is simply a part of who she is. Her integrity and passion for life is carried through to her role as a midwife

This story is one of joy, relief, excellent communication and respect, as was shown to a couple, John and Mary, by the staff of three different hospitals involved with the arrival of their first child

to her role as a midwife. She is a great midwife because she is a great person. As my dad puts it, “She just loves people”.

I can't express enough love and gratitude for my midwife. I am grateful that she turned a potentially highly medicalised event into a highly significant personal event for me and my family.

Usually we see stars only at night, but this star does not need the darkness of a crisis to shine. Becky shines even in the light.

Great maternity care

This story is one of joy, relief, excellent communication and respect, as was shown to a couple, John and Mary, by the staff of three different hospitals involved with the arrival of their first child.

They were older parents who recently had a miscarriage. They live on an island and were concerned about the distance to the mainland if labour started during the night.

The couple expressed their concern to the midwife about the distance between the island and the mainland should Mary go into labour during the night. The midwife suggested Mary be admitted to the hospital a few days before her due date so that the staff could monitor her and the baby and they wouldn't have to worry about getting caught out in the night.

Mary went to the hospital several days prior to her due date as arranged. A consultant explained to the couple that there were concerns about what appeared to be a significant loss of amniotic fluid around the baby that he was worried might cause some difficulty during the birth. The consultant was quiet, thorough, and gave them as much time for questioning as they needed. He recommended an ultrasound scan. The couple found his patient and quiet manner reassuring and felt safe and secure with his care.

Following the ultrasound the consultant recommended delivery as soon as possible. He suggested that they could go home for the night, but on learning about their circumstances agreed that they could remain at the hospital.

The couple had wanted a natural delivery so they contacted their midwife to ask her opinion of the consultant. She confirmed that he was cautious and did not believe in any invasive procedure unless it was necessary. This reassured Mary and they accepted they should follow the consultant's recommendations.

The following day the consultant visited them and whilst he was compassionate he was also very firm in saying that they had to induce Mary as the baby had to be delivered that day. They contacted their midwife and she agreed to come to the delivery suite to assist with the induction and stay for the delivery.

The key thing which stood out for them was having a nurse allocated to them who remained with them for the duration of their stay. She was able to explain everything that was happening and the reasons why

Several hours after Mary had been induced the midwife noted that there was a slight abnormality with the baby's heartbeat. A probe was placed on the baby's scalp to monitor the oxygen levels. The consultant quietly outlined the need to prepare for an emergency delivery. While Mary did not want to have an epidural unless absolutely necessary, she agreed that they could insert the line so as to be ready should an emergency caesarean be needed. An anaesthetist was called and he explained that there was a concern for the baby's welfare as the baby had reacted to the drugs which had been given to Mary to hasten labour.

At one stage during labour the midwife became concerned and hit the assistance button in the labour suite. This action caused the couple to fear for the safety of their baby. However, great care was taken to explain to them what was happening so they were fully informed.

Eventually the baby was delivered safely and Mary was discharged from the hospital to a smaller maternity centre. However, 12 hours later the baby vomited bile and needed to be transferred to another hospital where a barium swallow was done.

They found the staff at this hospital wonderful. The key thing which stood out for them was having a nurse allocated to them who remained with them for the duration of their stay. She was able to explain everything that was happening and the reasons why.

There was an attempt by a registrar to insert a line into the baby and after a third unsuccessful attempt, the nurse explained that their policy was for another registrar to be called to insert the line so that all concerned would not become distressed. The couple appreciated this approach.

Once the baby's wellbeing was dealt with, they were transferred back to the small maternity centre to receive breastfeeding support.

Today the baby is happy and healthy. The couple are grateful that their whole experience was one of respect, support and communication and that all the services including their midwife worked together so well in the best interests of their family.

A story of bereavement and compassion

Tucked inside my bedside cabinet is a very special photo album. It is very small and has only a few photos, a lock of hair and some hand/foot prints in it. These are of my baby son Frank.

Frank was born three months premature because I had unknowingly contracted Listeria. He lived for twenty-four hours almost to the minute. What began with such hope and promise ended with tremendous loss and a sense of a lost dream.

However, thanks to two very different hospitals, one an acute

The paediatric staff were fantastic. Not one of them judged us in any way, they were gentle in their questioning of us, they showed warmth in the way they touched us, in the way they made lots of eye contact, soft smiles, smooth and unhurried voices... they were incredible

provincial hospital and the second, a large city hospital, and their staff, my tragedy had many positive moments.

At my local hospital, because three years before I'd delivered my first son at thirty-two weeks gestation, Frank's signals that he too wanted to arrive early were not really surprising. The only indication that something was not quite right was that I had a temperature.

Over the next three days it became clear to my obstetrician that Frank was not going to stay put. Eventually it became clear he was actually in distress so I was to be flown to a city hospital – a long way from home.

The complication for me personally was that my husband and son were holidaying out of the country. I had accepted my obstetrician's advice and not gone with them due to my previous premature delivery. What was even worse was that they couldn't get back due to fog. However my wonderful mother travelled with me. The local hospital staff were so caring and supportive – lots of hugs and whispers of best wishes. Even the obstetrician gave me a squeeze.

At the city hospital, I expected to be just another case load. In fact, quite the opposite happened. The specialist looking after me had actually been on his day off and had come in to see me straight away. He was apologising profusely for his casual clothes as he bustled into the room. His warmth and attentiveness immediately put me at ease – I knew I could trust him. I was tired after three days of anxiety and contractions, and I was just so ready to hand over to someone – and he was it. He felt like a guardian angel. I'd left all my trusted carers at the local hospital, so to find someone special when you are most vulnerable and scared is hard to describe.

When Frank was born, it immediately became evident that he was very, very ill. Over night he had a number of seizures and by morning it was clear that he was probably brain dead. By the time I'd undergone an emergency caesarean, my husband and son had arrived so they at least got to see him before he died. And for my mother, there were others to help support her with the fear and uncertainty.

In the neo-natal unit, Frank had every monitor imaginable strapped to his wee body and every time they had to do something else to him, it was obvious to me as his mum, that he felt it. After talking with my husband, we asked if Frank could be taken off the life support.

The paediatric staff were fantastic. Not one of them judged us in any way, they were gentle in their questioning of us, they showed warmth in the way they touched us, in the way they made lots of eye contact, soft smiles, smooth and unhurried voices... they were incredible.

The cleaner turned to me and said: "I know and he just looks so beautiful." My heart swelled with pride because he was and how lovely of her to say that. I will always remember her

As Frank lay dying, the paediatrician – a lovely young woman – actually cried. For me, this was just so validating. It was an affirmation that my wee boy was a precious life and he was going to be a precious loss. He was quite simply, worth crying over. And to have a clinical person who must see death every day, have the compassion and courage to show her sadness, was quite simply heart warming for me at my most dreadful hour. I will always remember her.

One other staff member stands out – it was one of the cleaners. I had to remain at this hospital for a couple of days while arrangements were made for me to fly back with Frank. The staff had wrapped him up and put him in a wee cot beside my bed, where he stayed for my entire stay. A cleaner came in one morning and had a peek inside the cot. I immediately felt the need to protect my son from someone's adverse reaction and I quickly explained that he had died. The cleaner turned to me and said: "I know and he just looks so beautiful." My heart swelled with pride because he was and how lovely of her to say that. I will always remember her.

Other nursing staff ensured that lots of photos were taken of him, foot and hand prints were taken and a small lock of hair was snipped and tucked inside a piece of tissue paper. This is not something that I would have thought of at the time. A number of years on, I still treasure that small piece of black hair. How neat, because my other son was born bald and is today blondish. Frank was his own unique self and I have physical proof!

Back at the local hospital, the entire maternity team met me at the door. They'd found some beautiful miniature clothes for Frank and a wee cane Moses basket for him to lie in until his funeral in two days time.

Not one of them treated us differently – they'd laid a mattress on the floor of my room for my husband who was exhausted. They welcomed my other son as if he were any other little brother visiting his newborn sibling.

Each and every one of the staff at both hospitals made a difference for us and ensured that we now have some lovely memories wrapped around the birth and death of Frank.

Seamless care between home and hospital

Horror stories about pregnancy and labour abound. During my pregnancy with my daughter I made a conscious choice to screen these out, and to only focus on positive stories. I am now very happy to be able to share the story of the wonderful care we received during my pregnancy, labour, and afterwards.

I gave birth to my first child at home. We had an excellent homebirth midwife who supported and cared for us throughout the pregnancy.

Here were two women who could move seamlessly and professionally between an intimate homebirth and a busy public hospital

My labour was uneventful and I delivered a healthy baby girl at home in the early hours of the morning. We are all admiring her when what I felt a huge gush of blood. I just had time to tell the midwives what had happened before my blood pressure dropped very low and I had to lie down. Speaking or moving was suddenly a great effort, but I was perfectly aware of my surroundings. I could hear the midwives setting up a drip and calling the paramedics, responding calmly and efficiently to the haemorrhage. Soon we were at the local hospital, where my midwives continued to care for us while they waited to hand us over to hospital staff. They made me a milo and some toast, and examined me while explaining what had happened. They must have stayed with us for a few hours. I remember them finding my husband a mattress to rest on once a room had been found for me. Here were two women who could move seamlessly and professionally between an intimate homebirth and a busy public hospital.

Once the handover was complete, the excellent standard of care continued. I had to have an operation to halt the bleeding, and then a blood transfusion. This took place in the afternoon, 5-6 hours after my daughter had been born. I had had little contact with her since I began to haemorrhage. The consultant overseeing my care took the time to find out whether I had had skin-to-skin contact with my baby. When she realised that we had missed it in the rush to the hospital and the subsequent treatment, she made sure that we got it. I will always remember her bringing my daughter to me, stripped down to her nappy, and putting her on my chest. We slept like that for three hours and it is one of the most treasured memories I have. I will never forget that consultant's thoughtful actions.

I stayed in hospital for three days, and the two midwives on shift during that time who cared for me were wonderful. They always had time to chat, and were generous in making extra cups of tea and bringing food at odd times. They helped us give our daughter her first bath, and kept an eagle eye out for post-partum depression – they were concerned for this due to my significant blood loss. I felt absolutely fine in myself but they made a referral to the maternal mental health services anyway, 'just in case.' What stars.

Even the cleaners were lovely – coming to peek at my daughter and admire her. While I would still prefer to birth at home, I have lost some of my fear of hospitals as a result of my post-partum care and cannot speak highly enough of the calibre of the staff who treated us. I hope others have a similar positive experience.

Mental health services

Great community support instead of admission to hospital

Rose is a professional woman in her mid fifties who has suffered from depression and anxiety over the years. She considered this was well managed and did not impact on her ability to do her job.

Following a particularly busy year, she was aware that her depression was not responding to the usual GP visits and self care, and that she was not coping with the increased workload expected of her. Fearing that she was 'losing the plot' she endeavoured to keep abreast by working extra hours, but became aware of many mistakes she had made recently in key areas of her work.

Rose visited her GP and explained her concerns. The GP immediately sent a referral to the local community mental health service requesting more 'expert' care.

Three days later Rose was telephoned about the referral by a member of the Psychiatric Emergency Home Treatment (PEHT) team.

Rose was invited to meet with the team prior to the appointment to see the psychiatrist. At this visit she was encouraged to talk openly about her life and her job. As a result of this an urgent appointment was made to see the psychiatrist the following day. She was also given contact details for the team and reassurance that they would be following up after the appointment.

Rose explained that because of longstanding anxiety issues, she was unable to accept any suggestion of inpatient care.

The psychiatrist advised Rose that as a team they felt her depression and anxiety needed urgent treatment. The medication she had been taking for seven years was no longer working and there needed to be a planned reduction in that drug and introduction of a new drug, over a three week period.

Because of Rose's aversion to inpatient care, the team agreed to manage her as an outpatient and make every effort to support her to continue working. The team members visited daily at first, which gave her the opportunity to talk over the reactions and side effects she was experiencing and receive reassurance.

The team members gave advice on managing the effects and reiterated they would respond at any time day or night if required. They continued to visit her home frequently until after six weeks she was given the 'all clear'. She currently sees the psychiatrist two monthly to ensure all is going well.

This was such a successful approach, enabling her to carry on with her life without the disruption of an admission to hospital. Had she

The team members gave advice on managing the effects and reiterated they would respond at any time day or night if required

been aware of the level of care which was freely available, just by asking for help, she said she would have contacted the community mental health service a whole year earlier!

A wonderful residential facility for people who are mentally unwell

I entered my seventies happy and feeling fulfilled with my family, relations and wide variety of activities physical, social and intellectually challenging. But that started to change imperceptibly at first to greater depths of unease and personal feelings of inadequacy and inability to cope with age in its seemingly large looming problems both physically and emotionally. When either my husband or I felt 'blue' we found that dropping everything and taking off in our car for a week or so sightseeing, walking, golfing and visiting distant friends and places meliorated and revitalized us.

However I became skeletally thin and a worry to all who knew me. At that point our long term GP, who is a very caring and knowledgeable person, took a very active interest and intervened successfully, with a combination of medication regimes.

About three very fulfilling and happy years followed. Both my husband and I really enjoyed a very happy period that turned out one of the best times in our life in all respects. People told me that I was the picture of health and that is the way our offspring saw us.

With the arrival of the long miserable winter accompanied by clinically depressing emotions extending to some suicidal thoughts we turned to our usual trips away as well as long walks to interesting places, entertainment etc. with disappointing results. My later seventies were becoming markedly miserable

Our GP promptly started changes in medication but without great effect and some worsening of side effects at times. Being very up-to-date in his approach he suggested the people at a specific residential facility would probably arrive at solutions before he did and made a prompt referral to them. Within a few weeks the results were outstanding.

Two psychiatrists visited us at home for a preliminary discussion, which was warm and friendly. One doctor has a marked sense of humour as well as a knack of getting to the heart of the situation. The successes, the failures, the increasing black times etc. It was as if we were friends rather than professional and interviewee. In the subsequent meetings with her and her nurse assistant that same atmosphere prevailed and information flowed both ways very freely. A wide array of clinical tests were recommended including scans to exclude an extensive range of physical and neurological possibilities

One doctor has a marked sense of humour as well as a knack of getting to the heart of the situation.

Some medication and tests were unpleasant but this was unpleasantly fraught in the short term but this was counterbalanced by the understanding and frank discussion in which we engaged. The outcomes have been truly great and I am delighted that once again I am living a full and enjoyable life. Naturally I am intensely grateful for all the staff at the facility who have helped me to achieve these results, as of course are my family and friends.

As a lifetime registered nurse I really appreciate the professional knowledge, application, adaptability and warmth exhibited by the staff particularly my allocated psychiatric nurse. This is the sort of service the public can put their faith in.

Making a difference with aroha

In the last few years, my mental, emotional and physical problems seem to have become steadily worse despite my efforts to get help.

After a suicide attempt I ended up in the mental health service and was put on a course. Although this was useful in creating some stability, I didn't receive any psychoanalysis or psychotherapy so my problems continued.

Eventually a social worker referred me to a special mental health facility. I was at my lowest and had they not taken me in, I would have probably attempted suicide again.

Two days later I was already able to see some light at the end of the tunnel. How come? AROHA!

The staff are some of the most caring and loving health workers I have come across. They are there for me all hours of the day and night and have enough experience to be able to assist in emergencies. I have had a few serious lows due to the lack of listening skills of psychiatrists and psychologists, but the Aroha of the staff has always been able to turn me towards life again.

Medication can help, but without Aroha life is not worth living (speaking for myself). Aroha does not come out of text books – it comes from the tupuna and originally from te Atua – God, Goddess or whatever is the creator.

This facility embraces the 'Tapa Whaa' model and healing is 'allowed to take place' rather than strategically forced onto people. The staff work "alongside the client" and awhi to the best of their ability.

Whakamoemiti kia koutou Mihi Aroha kia Koutou

I have had a few serious lows due to the lack of listening skills of psychiatrists and psychologists, but the Aroha of the staff has always been able to turn me towards life again

With the help of a caregiver and support from a local society I managed to get back on track, move into a flat and hold down a job for a number of years.

Care and support that stands out

I have had a mixture of care and treatment from mental health services over the years so great care really stands out. The staff of one hospital I was admitted to provided excellent care and made sure I was on the right medication before I was discharged to a halfway house so I could get back on my own two feet again. I was then treated really well by great staff at the halfway house. With the help of a caregiver and support from a local society I managed to get back on track, move into a flat and hold down a job for a number of years.

When someone I met persuaded me to come off my medication the results were disastrous. Fortunately the local crisis team quickly sprang into action and got me back to normal so I could resume my job. The support and care I received from all these people was of a very high standard and I am a stronger person now.

Palliative care

HOSPITAL

Making a difficult time so much easier

As a whanau we have been incredibly happy with the outstanding level of service provided to our father. We have spent a lot of time with him in and out of different health care facilities over the past six months. The service provided by the hospice staff has been the most outstanding of all.

We have appreciated how swiftly the staff respond to the call bell and the care they take to wash their hands and communicate with us. We appreciate that they also take the time to explain our dad's condition to us and make the extra effort to keep him updated as well. We have found them to be extremely knowledgeable, patient, caring, respectful and considerate of our father's needs.

The facilities are very family friendly as well as being clean and tidy. At such a difficult time we are so very grateful that such a place is available and we will always remember the fantastic care you provided. Your hard work and goodwill have helped bring comfort at the most troubling time in our lives.

A very special end of life journey

When our special and much loved mother became terminally ill our family were determined to care for her at home. We felt she would be best loved and cared for in familiar surroundings with her own family and comforts around her. After nearly six months of caring for her at home she became increasingly immobile. We were forced to accept that the time had come for a greater level of care than what our love and best efforts could provide.

We sadly and reluctantly accepted a placement for mum at a local rest home. We had expected that the care provided would be kind and competent. What we didn't expect and were delighted to discover, was that the staff were genuinely interested in all aspects of mum's care. They were very loving to her and very supportive of our whole family.

I was able to continue to visit mum every day, often quite late at night on my way home from work. I was still able to be involved in her care, and could now go to work confident that she was safe and loved. I knew I would be contacted if there were any concerns or any decisions to be made. I had the freedom to be a daughter again, and could also assist by supporting her nursing care.

One of the nurses introduced a daily nursing diary. This enabled the staff to comment on how mum had been during the day, recording precious moments and fun remarks she had made. They also used it to request any extras that she needed. I recorded any concerns or questions that I had each evening and would comment on how she had settled each night. We now have a very personal, precious and detailed record of mums last few months.

My father, who was ill himself, was welcomed by the staff who took an active interest in his comfort and well-being. During his frequent visits dad was able to snooze quietly in the lazy-boy chair, hold mums hand or occasionally nod-off in the bed next to her. Dad has dementia, and although he often did not make sense or respond appropriately, he was always treated with dignity and respect.

Family members both old and young were all welcomed and encouraged to visit. My younger sister was able to fit in visits to mum around the demands of managing her family. She could concentrate on enjoying the time spent with mum, uncluttered by any responsibilities for her day-to-day care. My older sister living overseas could ring up at any time to get updates on mum's care and also speak with her directly. My brother was also welcomed whenever he was visiting from out of town.

When mum deteriorated and entered the final few days of her life, my sister and I were able to be with her round the clock, assisting

What we didn't expect and were delighted to discover, was that the staff were genuinely interested in all aspects of mum's care

The very personal and homely atmosphere, the wonderful food and warm welcome to us all, provided the next best thing to having mum at home

with her care, sleeping in the lazy-boy chair, and being part of supporting mum and each other through this sad and very precious time. The staff were amazing – sensitive to our needs to be both private and supported, and tolerant of the disruption of having us around full time for seven days.

The very personal and homely atmosphere, the wonderful food and warm welcome to us all, provided the next best thing to having mum at home. Most of all we were truly blessed by the genuine love and care shown to mum and in the way the staff supported the whole family in this journey by sharing in our sorrow and our laughter.

Rest home care and services for older people

A niece writes about her aunt's care at a rest home

My aunt was diagnosed with a terminal illness. I initially cared for her at home until her care needs became too much for me so she went to a rest home of her choosing. However, when members of our family went to visit her late on the day of admission, they found her in a distressed state and took her home straight away.

We then approached a second rest home, for a trial period, so they could make sure my aunt's needs were being met. My aunt was a very refined lady who was used to being surrounded by nice things. We advised the rest home manager we would reassess her placement frequently to make sure her needs were being met. We also told the manager that when she required terminal care, my aunt had expressed her desire to go to a hospice for her last days. The manager agreed to this course of action.

The rest home environment proved to be great. It was spacious and clean with easy access to the garden. The more alert residents were in a separate wing so they could participate in stimulating conversation with each other.

The staff were all very kind and caring. They catered to my aunt's needs, attended promptly when she called and never made her feel she was asking too much of them.

Because my aunt was a person who wore makeup daily, was always immaculately coiffed, with her nails groomed, the staff made the effort to maintain the standard she was used to. She was particularly happy that the staff did not insist on her staying up when she preferred to be in bed.

When she could not eat a lot and did not feel like normal meals they made her special snacks like fruit kebabs.

Because she was terminally ill, they encouraged hospice staff to

They catered to my aunt's needs, attended promptly when she called and never made her feel she was asking too much of them

maintain regular contact with her and when it became apparent the end was near, they instigated her transfer to the hospice as agreed.

In addition to all the wonderful care my aunt received, the rest home staff were also very kind to our family. They were always available no matter what time of the day to discuss any aspects of care or concerns our family had and were always willing to accommodate special requests.

Coping with dementia made easier by flexible and responsive services

The day I found dad standing in the hallway with his false teeth in a jar, his vivid blue eyes clouded with anxiety, and looking like he was not quite sure what was happening, I knew his battle with dementia was beginning in earnest.

He was off to see a plastic surgeon about some lesions on his face and head which were being monitored, but he did not understand that, or that he needed his teeth in, not out. Watching him shuffle toothless through the hospital corridor, I hardly recognised the father I had loved for so long.

Our path through end-stage Lewy Body Dementia had well and truly commenced. It was a journey I would not wish on my worst enemy, and was far more harrowing than any of us could have imagined.

What saved my sister and I, his main caregivers, from despair was the support and partnership offered by the health professionals, and home support carers, who were with us all through the last eight months of dad's life.

It was in late autumn, early spring, that we realised we needed more help for dad than the existing medical support he was receiving for his heart and a Parkinson's-like condition that made it difficult for him to walk, write and do household chores.

The consultant geriatrician from the local district health board came to his home to do an assessment. This meant dad could be tested while sitting in a setting he found comfortable. The consultant was quiet, respectful and very thorough. So too was the community-based nurse who saw him before and after this consultation. My sister and I took turns at acting as go betweens – my father's deafness and deteriorating condition required that – and to reassure him.

We were told that dad had some cognitive impairment. That became very obvious when he started seeing things and calling the police when he thought his home had been broken into at night.

A couple of months later he called 111 after having 'a turn' at home. He was admitted to hospital and became highly agitated overnight. When we arrived the next morning he was verbally aggressive, yelling at us to get out and that he never wanted to see us again.

What saved my sister and I, his main caregivers, from despair was the support and partnership offered by the health professionals, and home support carers, who were with us all through the last eight months of dad's life

Dad did come home, and his obvious joy at being back made the collective effort to keep him in the community so worthwhile

In shock, we sought advice. It was mid-December at this point and with the Christmas holiday period looming, it took real effort from the hospital team, and community-based support team to sort out a care plan.

With dad adamant that he would not move to a rest home, the hospital rallied and found him a bed over Christmas in their rehabilitation ward, giving us time to organise extra help for him at home in the New Year.

Dad did come home, and his obvious joy at being back made the collective effort to keep him in the community so worthwhile.

It wasn't easy as the effects of his dementia became more pronounced and my sister and I continued to work full-time, care for our families and help look after dad. He did, however, accept a caregiver coming to the house each morning to check on him and do basic care and housework. This was a huge bonus, as was the regular feedback from the community nurse about dad's status.

It was a hot summer, and those were precious months where dad was able to potter around the garden, sit in his chair and doze, and spend time with us at 'his place'. I am sure the familiarity of his surroundings made it easier for him to cope with the changes that were happening in his brain.

Lewy Body Dementia is not a 'steady state' disease, and as summer wore on it was clear dad was getting worse at a faster rate. He was falling over quite frequently, finding it hard to eat enough and having hallucinations, particularly in the evenings, which led him over to the neighbours who would call us.

My sister and I slept fitfully in our own homes, never sure what each night would bring and frequent 40 minute drives to dad's house were needed so he could be settled.

Easter came, and we experienced another crisis. A neighbour's child found dad walking up their shared driveway at dusk with blood on his leg saying he had fallen over and was waiting for his daughter to collect him. There had been no call and without our neighbour's alertness dad could have been in real trouble.

Dad stayed at home, but it was clear this would soon be unviable. My sister and I had a roundtable discussion with his consultant, the community nurse and a social worker. It took time – more than an hour – and we thoroughly discussed the pros and cons of the options facing us.

We were gently told that it was their legal responsibility, not ours, to ensure dad was safe. Knowing this made it easier for us and we all agreed that it was time to broach the rest home option again.

I knew how painful dad would find this transition and left it to my sister and the community nurse to talk him through it. The day

We slept soundly for the first time in months. "Dad is warm and safe," was all I could keep repeating to my kids

came and we were surprised. "You got me on a good day," dad said. "I woke up this morning and didn't know where I was and thought I had to go to work," he explained, a shock no doubt as he had been retired for almost twenty years.

It took all day, but in the end dad went up the road to a local rest home and we slept soundly for the first time in months. "Dad is warm and safe," was all I could keep repeating to my kids.

The transition did not go well. He was lost and disorientated away from home and, I think, filled with despair that things had come to this. He started hitting the staff with his walking stick and attempted to leave after three days. After his first escape attempt he was bought back by police. We spent the day with him and he seemed unsettled and distrustful.

Early that evening he shuffled off again, and by the time we were told he had disappeared the light was fading and temperature dropping. We knew that if we didn't find him by nightfall he was in serious danger. A neighbour found him about two kilometres from the rest home, moving determinedly in the direction of home, and took him to hospital.

That was the last time dad experienced freedom. The next, and last, three weeks of his life were a nightmare for everyone, although the wise counsel and partnership offered by medical staff was unstinting.

Dad was agitated and, eventually, needed to be sedated. Those medical terms sound mild enough, but the reality was that dad was either spending most of his time trying to pull down curtains, bite nurses or hit people, or he was comatose. There seemed no middle ground.

He was shifted to the same rehabilitation ward he had been in at Christmas, and having the same staff care for him – people who knew him when he was still with it – made a huge difference to us. "Your father is a lovable rogue," said one of the nurses as she prised his hand off the rail he was stubbornly clinging to.

The consultant had another long talk with us and we agreed that if something happened to dad we did not want him to be resuscitated. Having come to know her very well made this awful topic so much easier to discuss. She knew how much we loved dad, how we hated to see him suffer and we all understood the decision was made with love and seemed right in the circumstances.

After two or so weeks largely spent under sedation dad woke up. The next day, when my family went to visit, dad rallied and showed us that despite everything his dignity and kindness were still intact. "I am sorry you have to see me like this," he whispered to my husband, and had tears in his eyes as he smiled and briefly hugged my children. "Don't wear yourself out worrying about me," he said to me.

We only hope that other families who have to deal with their family members in similar circumstances have the opportunity to experience the same high level of care and professionalism that helped us through dad's final journey

I saw dad alive for the last time two days later. It was my birthday and my twelve-year-old son and I went to visit. He couldn't speak, but reached out and hugged my son. He was in a wheelchair and a shadow of the person he had been even a few weeks before. At that point, I knew the dementia had won.

Two days after that I received a call from my sister at the hospital. Something had happened to dad and I needed to get there straight away. Twenty minutes later I arrived, a minute or so after he died.

It didn't matter – my first words were that I was happy dad had died and his suffering had ended. The staff were very kind. Several family members came out and we had as much time as we wanted with dad. That made a big difference. The kids had a chance to see him while his body was still warm and he still looked like granddad. They gave him a hug and said goodbye.

Looking back, caring for dad through his journey with Lewy Body Dementia was extremely stressful and emotionally draining. What made it bearable was working as a team with my sister, dad's courage and determination, and the partnership we developed with the medical team who cared for him in hospital and in the community.

They got to know him and us before things got bad and the trust and respect this created meant that when the going got tough we all pulled together.

They gave him and us time – time for dad to spend at home, time to discuss the different care options.

The team was also flexible in accommodating his needs. Allowing dad to go home after Christmas was probably not the best option, but it was what he desperately wanted and they worked with us to make that happen.

The same went for having him in the hospital's rehabilitation unit rather than a regular ward. The atmosphere was very different and the goal for all patients was to 'go home', the only option dad was really prepared to consider.

We only hope that other families who have to deal with their family members in similar circumstances have the opportunity to experience the same high level of care and professionalism that helped us through dad's final journey.

A residential paradise

Ruby was married shortly after her fiancé, Jack, returned from World War 2. They lived all their sixty years of married life in the same small home, managing on a war pension. The house was original, except for the replacement roof, new piles and several new windows and weatherboards. They spent a lot of their Fridays at the local

Ruby has stated that 'it (living in a rest home) should be compulsory' and that she feels like royalty as she is treated as if she is

auction, buying splendid pieces of crystal and china to adorn their front room.

Sadly a few years ago their health started to deteriorate and Jack died. The house was in the process of having a wet area shower installed.

It was suggested to Ruby, that she may like to spend a couple of weeks in a residential facility whilst this work was being completed.

She reluctantly agreed to an 'up to two week' holiday in a local residential home and took to it like a 'duck to water'. Within the first week she had been out on two bus trips to places she didn't know existed, had her hair cut and set, and her niece had taken her shopping for two new trouser suits. She told me that she felt like she 'had arrived in paradise'.

Needless to say, Ruby has not returned to her home and didn't even want to visit it before it was sold. She loves the activity and the company she gets from other residents, staff and visitors. She has met friends from her younger years, both as residents and their visitors and although she misses Jack, her only regret is that they couldn't have spent their last few years in this home together.

Ruby has stated that 'it (living in a rest home) should be compulsory' and that she feels like royalty as she is treated as if she is.

An eighty-seven year old woman tells a health and disability advocate about her wonderful life and care

When I met Jean in her rest home, she shone out from the group in the lounge, her hair beautifully set and bright pink lipstick, with matching nail polish setting off her turquoise twin set and navy skirt. She was eager to tell me her story and what a privilege it was to hear it.

Jean was born in 1920, after a very difficult birth. Neither she nor her mother was expected to live, but Jean's survival is a testament to the passionate devotion of a dedicated plunket nurse. They have become life long friends.

Jean has Cerebral Palsy affecting her right side. For most of her early years she wore callipers on both legs and walked with the aid of crutches. She tells me that when she was in her teens a doctor suggested she try wearing only one calliper and using a walking stick, Jean found this liberating and quickly found a new freedom. She succeeded at school and left school to work as a telephonist in a large rural mercantile firm. In 'those days' people with disabilities were hidden from the public.

Redundancy in the sixties meant Jean had to seek other employment and successfully become the lift operator for a large department store,

She told me that she has a bright view from a lovely room, good meals, great company and it is like living in a hotel or being on a cruise ship with planned activities and entertainment, a hairdresser on site, church services every week

ferrying customers up and down the three levels of the store and getting to know many generations of mothers and children, as well as the elderly customers who would spend several hours each day in the store for company and the warmth of the store during the winter. Jean felt sorry for these older people and hoped that she would never need to become like them, lonely, cold and for the most part poor.

When she retired, she built a new home, designed for her particular needs and settled comfortably into retirement like the rest of her 'group' of mainly single women. One by one her friends became sick and died, leaving her the only surviving member of this elite group. She organised for a lady to come in a few days a week to help her in the house and garden. On one of these occasions, she arrived to find that Jean had fallen out of bed and couldn't get up. She was taken to hospital for treatment followed by discussions about the arrangements for her long-term care.

Jean was given a choice of going home with extra support, or trying rest home care. She decided on the later as her only living relative was in a cottage attached to the rest home and she thought it would be great to be able to catch up on past family times. She was delighted to arrive at the rest home and be shown her room that looked over the garden into her cousin's front door. She told me that she has a bright view from a lovely room, good meals, great company and it is like living in a hotel or being on a cruise ship with planned activities and entertainment, a hairdresser on site, church services every week.

Recently, Jean picked up a new pair of shoes with a lighter calliper and is getting around like a 'spring lamb'. She told me she doesn't have disabilities, just different abilities and keeps herself busy using her talents and skills such as making dozens of pompoms for the Christmas stall.

Great care transforms a life of isolation

Our mother reluctantly moved from a large city to a provincial town at the age of ninety-three years and suffering from dementia. Almost her whole life had been lived in isolation and she did not socialize outside her home. She had always been strongly independent and very critical and judgmental of others.

It was however a truly amazing experience for us, as a family, to see our mother accepting real warmth, love and enjoyment during the last two years of her life before she passed away, a widow of fifty years.

The staff share the most wonderful culture of respect, consideration, warmth and love in their care of all the residents in both the rest home and hospital wings. Within a few short weeks we saw the

amazing changes as our mum began to settle in and make friends among both the residents and the staff.

We are very grateful to the people who make places like this rest home possible. We have personally thanked them all.

A family's experience with dementia

My father was admitted into a dementia care facility when he was eighty-nine years of age. He had been deteriorating markedly over the preceding twelve months. He would forget how to make his way to the bedroom, and believed there was another woman living in the house (who had the same name as our mother) who was stealing his money and driving the car. He also started to have distressing hallucinations such as birds coming through the ceiling. Our mother's health was deteriorating as a result, so after consultation with the community mental health team for older persons, we decided that dad needed to be admitted for assessment for suitable ongoing care.

We knew that removing dad from his family and admitting him to hospital was going to be extremely distressing for him, and so it proved. When dad was in the acute mental health ward for older persons, the staff found the only time he would settle was when he was with his family. We visited every day, borrowed a wheelchair and took him to the coffee shop and for walks by the lake. We made a photo album with all photos identified with attached stories, so that the staff could talk to him about his family to calm him.

After six weeks in hospital, dad was transferred to the rest home that specialised in dementia care. It was not the facility preferred by the hospital clinicians who believed that this facility would not be able to manage him. However, from the very first day, dad was treated with dignity and respect. We were encouraged to place familiar items in the room he was to occupy, such as photos, pictures and furniture. When we left him that first day and he became distressed, the owner/manager spoke quietly to him and massaged his hands to settle him. Over the next few weeks the antipsychotic medication and sedation was reduced, and although he remained distressed at being separated from his wife and family, he settled.

The rest home staff encouraged the residents to live as fully as their abilities allowed. We took dad for outings every weekend, for coffee, to smell the bush or to look and listen to the sea. His enjoyment of these outings did not diminish as his dementia advanced. The most memorable of these outings was the day we took him to the beach for a picnic and a swim. My sister bought him a new swimsuit for the occasion. My brother and brother-in-law escorted him into the water, and when dad was up to his waist, he surprised us by suddenly diving in. He was unable to swim like he used to, so my brother towed him round. It was a time to cherish.

The rest home staff encouraged the residents to live as fully as their abilities allowed

Not long after that dad fell in the rest home and broke his thigh, and was admitted to a public hospital for treatment. A consultant anaesthetist came to talk to us about the problems associated with giving dad a general anaesthetic and we talked about our expectations for his post-surgical care, which was getting him through the surgery and back to the rest home as soon as possible. I went with dad to theatre to keep him calm until he was given the anesthetic. The orthopaedic surgeon who was to perform the surgery explained to me that there was no option but to operate. As I began to explain the family's wishes regarding dad's acute care, the consultant anaesthetist appeared and said that he approved of this plan. I was impressed by the manner in which all the clinicians involved in dad's care respected him and listened to the family's wishes. Dad was transferred back to the rest home four days after the surgery.

He is now 91 years and at the end of his life, and has not been able to leave the home for more than a year. He no longer knows who we are, but we think that he senses a familiar presence when we visit, with our coffee and cake. We will miss him dreadfully when he dies, but we are grateful for the opportunity his illness has given us to create special and lasting memories of our lovely dad.

Enjoying the benefits of an 'extended family'

Ninety year old Ruby had always kept good health and never ever thought of going into a rest home. She had served overseas with the NZ Army for eighteen months and puts her ability to fit in anywhere down this training.

After the war, she married and raised three children and continued to live an active independent life when she retired at sixty until she was eighty-seven. At this time, a medical event led to her GP referring her to hospital for surgery, where signs of early cancer were found and operated on.

After surgery, Ruby was transferred to a local rest home for recovery. During this recovery period, she fitted in so well she simply decided to stay where she was. She considers herself lucky as she has all the benefits of a large extended family with both residents and staff.

She enjoys the outings and other activities organized by the home. She particularly loves the library and being able to choose what she wishes to attend.

Staff pop in and share stories and jokes with her. Ruby can't understand why anyone would want to complain as there is good food, company and outings. She can just get on and enjoy life. Despite the heavy and tiring work, she has never heard any of the staff speak rudely to a resident.

Ruby can't understand why anyone would want to complain as there is good food, company and outings

Home away from home

Ninety-seven year old Rita had been living with her family for a few years until her move to rest home care three years ago. Discussions had already taken place about moving in to the rest home of her choice and arrangements were made. The final morning at home she stepped out of shower, fell and split her leg, ending up in hospital for ten days.

She was then transferred to the rest home for recovery. Once recovery was complete, and it was confirmed that she met the criteria for full time rest home care her decision to stay where she was, was simple – as she was already in the home of her choice.

Rita feels like it's 'a home away from home'. She can do what ever she likes and joins in outings, activities etc whenever she wishes. This is a continuation of the wonderful life she has had raising four children with a wonderful husband until his death at age seventy-seven.

She enjoys the company of the large extended family, the good food and being well looked after. She can also still enjoy past activities such as bowls and family functions, as her family take her out to these events.

A place to learn new skills

Eighty-nine year old Lucy had been a widow for eight years when she noticed she was losing interest cooking for herself and running her own home. She also had some health concerns and discussed moving into a rest home with her GP.

She rang her family and told them she had decided to sell up and move into a rest home that she had chosen. Her family was relieved and happy that their mum had made her own decision.

Having visited friends in other rest home and noticed some differences, her choice of rest home was made easy for her. By taking part in activities and outings, she keeps active and remains independent.

Now at ninety-three she has no worries and is happier than when she first arrived.

She has learnt new skills such as sketching, making cards and gifts. She modeled for the first time ever when she was ninety and had her photo displayed in the local paper.

She has been involved in games between other rest homes and loves the whole atmosphere of being with residents and staff. She continues to be amazed by the people she meets and the history and common themes she shares with them.

Lucy's goal is to live at least until she is ninety-six.

Rita feels like it's 'a home away from home'. She can do what ever she likes and joins in outings, activities etc whenever she wishes

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*May says she is
'enjoying the life of
being looked after
with courtesy'*

Being treated with courtesy is important

When eighty-three year old May ended up in hospital three years ago after being knocked off her scooter it was clear she was no longer able to return to live in her own home.

She was transferred to a rest home for recovery. When the time came for May to be assessed, she was invited to look at rest homes suitable for long term living. Unfortunately her health didn't permit her to do this, so her family helped out by checking the various rest homes on her behalf. They helped her move into the chosen rest home as a long term resident, where she has now lived for three years.

May has settled in and enjoys the company of other residents and all the staff. The meals are good and she particularly enjoys the van outings, and other organized activities.

She uses a walker which she describes as 'her life line', as without it, she would be unable to mobilize and get around. Now at 86 she remains as independent as she can, seeing family members in the area with other family members making contact as they can.

May says she is 'enjoying the life of being looked after with courtesy'.

Homely is better than posh

This home might not be the most up-market, but it is home for me. The small size of the home has the benefit of a family atmosphere where we can care for each other.

The great atmosphere among the staff and residents is so important. Staff are consistent in their bright and cheery approach even when things are difficult and they get tired. Nothing ever seems too much trouble for them.

During my own difficult time of having to live separately from my very ill husband who was in another home, I received tremendous support from the staff.

This home also doesn't 'smell' like some rest homes. A great deal of attention is paid to this issue.

Consideration for me as a person

Everyone including the staff and residents are considerate and helpful especially as I have limited eyesight. I love to listen to rugby matches on the radio so pills are never given to me until after the final whistle.

When I had a large painful ulcer on my heel the nurse would take great care to change the dressings without causing too much pain. She would also come in at weekends to change the dressings.

All staff were very considerate of this condition over the two months it took to heal. The caregivers would take care to keep the leg bandaged and look after the heel especially during shower times.

For me, it is about consideration for me as a person.

Having the freedom to make personal choices

Having the freedom to make personal choices for myself helps make rest home life more acceptable. Being able to choose to change into my dressing gown in the afternoons, and then to be able to go to tea dressed in this manner.

I also like to feel able to be part of the home's every day functions. For example I collect the morning tea cups, take them to the kitchen and wash up.

A letter from a grateful family

It was lovely to see you at mum's funeral. Thank you for coming and conveying your sympathy to us. You are very kind and it meant a great deal to us to have you there. Mum would have been pleased.

Thank you for the wonderful care, respect and love you showed our mother throughout the years she was with you. Without all the understanding, care and great patience you showed her, she would never have lasted as long as she did. Mum had six years with you and I feel we were very lucky as a family to have found you to look after her. You and your lovely staff are blessed people for the work you do. I cannot express to you how grateful we are for mum to have been cared by you all.

What a difference a change made

We made the decision to move our mother after she had been at another local rest home for seven years. The decision wasn't made lightly – and we as a family have to say that the transition was handled delicately in very trying circumstances. Having observed the new rest home at close quarters over the last nine months I am very impressed with their standard of care.

The home is run as an extended family home. The residents are treated with great courtesy as individuals with different needs. There is an underlying happiness that radiates with alert residents having the opportunity to participate in every day activities – as opposed to lining walls watching TV. There are colouring books, music, jigsaw puzzles and embroidery. Joining in is actively encouraged.

I am very impressed with how the caregivers gently ask the residents to come with them when toileting is required. This is not left to chance – being systematically undertaken with privacy and dignity.

Without all the understanding, care and great patience you showed her, she would never have lasted as long as she did

We feel extremely lucky to have mum in the right environment where love and care are paramount

Our mother recently had a fall during the night. We were rung immediately and updated from the hospital. The couple who own and manage the rest home stayed with my mum till 1.30pm to bring her home. I felt that this personal service was way beyond the call of duty and highlights the attitude of dedication and love that this couple and their staff share to provide that extra something. I visit mum at varying times and she has always been beautifully groomed in matching clothes with her hair smart, and ready for the day.

After experiencing dubious care at times at her last residence we feel extremely lucky to have mum in the right environment where love and care are paramount.

Being treated as an individual with dignity and options

Our father has been receiving rest home care for nearly four years. As a family we have been very pleased with the first class care he has received in this time. The staff treat him as an individual. He is not required to join in with planned activities if he does not want to. He is not stopped from walking round and round the garden if that is what he wants to do. We can tell he really enjoys the garden and the care he receives. The staff are gentle and tolerant with him. He always seems clean and cared for.

Members of our family of all ages visit him regularly. Although not necessarily at a pre-arranged time we are always welcomed and offered a cup of coffee. Special occasions such as his birthday are marked and staff assist the family to have a special meal with him in a separate area.

Observations of a funeral director

I feel compelled to write about a really special rest home. Having visited many establishments on a regular basis due to the nature of my work, I came away from this home feeling that I had seen and experienced a very special place even though I was only there a short time.

From the moment of walking in past the front gate and noticing the brightly painted ceramic pots and the very lovely garden – complete with silver beet, and meeting the residents – I had a sense of being at ‘home’ and could feel the warmth, love and care that emanated throughout.

The residents seemed very happy and contented and had a special sparkle about them that I have never seen anywhere else. This in itself made a big impact on me. The way the staff relate and interact with the residents was warm and genuine and was just so refreshing and lovely to see.

The residents seemed very happy and contented and had a special sparkle about them that I have never seen anywhere else

I can't really describe in words the feelings that I felt but if I had a loved one who had dementia I would want them to be looked after at this rest home because residents are treated so well and I could sense that they are very happy there.

Observations of a rest home entertainer

For the last five years it has been my pleasure to have been able to visit and entertain the residents of a particular rest home. Over the years I have come to realise and appreciate the enormous effort required and unstintingly given by the very special staff and management there, to provide the highest level of specialized care their residents have every right to receive.

The atmosphere is that of a large family with each member caring about the well being of each other. To create and maintain this atmosphere has, no doubt, taken an enormous amount of time, organization and effort and is working so well.

My visits have considerably changed my outlook on life and I feel privileged to know such people. These visits are always a delight for me when I see how the residents and staff dance and sing together. It's a time of fun and laughter and I would love to see it spread to all rest homes. I congratulate the managers and staff on the home they have created and sincerely hope they continue their excellent work.

I humbly suggest a week spent in a well run rest home such as this one, sharing in all the chores and activities, would be a richly rewarding and enlightening experience for anyone; particularly for those who monitor the legislative requirements for the safety and wellbeing of the residents. I believe such an experience would have huge benefits for all concerned and be more useful than the ever increasing burden of paperwork and other non-productive activities in order to satisfy the requirements for an operating license.

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