



# *Huntington's* NEWS

*The quarterly newsletter of the  
Huntington's Disease Associations of New Zealand*

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Issue 104

## *Annual Camp 4 Young People for those 12 years and over 28 September – 2 October 2009*

The proposed Camp for 2009 will be held from 28 September – 2 October 2009 at the El Rancho Holiday Park, Waikanae which is about one hour north of Wellington.

We welcome all young people from Huntington's families aged 12 years and over. As with past Camps, there will be a mixture of exciting outdoor activities as well as time to discuss and share knowledge on Huntington's disease.

El Rancho and the surrounding area offers a variety of exciting activities such as rafting on the Otaki River, rock climbing, abseiling, Go Carts, archery, sea kayaking, ropes course, orienteering and navigation, and many more!!

All interested participants should indicate their interest as soon as possible to assist us with the final planning process.

For more information, contact your local HD adviser, social worker or field worker (see Contacts list on the back page of this newsletter) or:

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# *Helping you help me take a shower*

*A note of thanks to my helpers and some ideas to make it easier for both of us!*

Hello, Partner!

This brochure is for you kind folks who will help me shower. My partners! You might be my spouse, a nurse aide, a friend or another relative. There are no special methods that you need to know just because I have Huntington's disease (HD). However, there are some easy techniques that you can use to accommodate some of HD's challenges. Many other folks with HD have found that they make showering easier and more comfortable for them.

When you need somebody to help you take a shower it becomes less pleasant than it was in the past. There are different reasons or combinations of reasons. Sometimes I simply wish I could continue to do it for myself. I've also learned that there are some universal approaches that some folks with HD and their helpers use to make the whole thing go smoothly again. More importantly, though, I've learned to avoid those ways that can be more irritating and annoying than they are helpful

## *What we've learned*

Many other folks with HD who need help showering like I do tell us that:

- They hate surprises. They'd like to know when the water's coming on, when you're going to wash their face and rinse their hair.
- They hate waiting for a towel, for soap or worse, for help!
- They've had unpleasant experiences in the tub or shower. Perhaps they've slipped or fallen. Maybe they've had people help them that have been no help at all.
- They want to know what to expect. It's likely that different helpers help in very different ways. Sometimes it's gone smoothly and others times..... aaarrggghhh!
- When the water's on, reassuring words are more helpful than reprimands or ever changing instructions.
- They want it done as efficiently as possible.
- It's easier if it's done the same way every time: in the same position, at the same time,. In the same order... with reassurance.
- They really want to know how much longer it's going to take.
- We need a handheld shower head so you, my helper, won't get soaked, too.

## *Helping you help me*

Now let me tell you a handful of things that will help you help me:

- Please remind me when it's almost time and when it is time to shower.
- Please understand my two most important concerns: that you've helped me position myself safely and that you have everything we need so that you don't have to leave me.
- Please give me a "heads up" that you're about to wash my hair, face, front and butt.
- Please give me a "play-by-play" of what you're doing and what we're going to do next.
- Let me know when we're halfway done, almost done and finished!
- Please use the same few instructions; it's easy to feel confused with all that's going on.

## *Getting in Position*

A professional baseball player comes to bat. He carefully places each foot in the batter's box. He checks his balance, his distance from the plate, his grip on the bat and readjusts his feet a bit. Only then does he look up, ready for the pitch. Let's do it the same way! We'll take as much time as needed to get safely in position, either standing up or in a shower chair. Making sure that the grab bars are within reach, that I have a wide base of support and that both of us are comfortable.

Now turn the water on!

## *Comfortable and Quick*

Folks with HD often find that it takes them a few moments to respond to questions and instructions; and a bit longer to pull our thoughts together. In the tight space of a shower stall, in a small bathroom, with water flowing and splashing, naked, it can get confusing very easily! Together we can do this comfortably and quickly. But it's easier for both of us if you tell me what's going on, what's coming next, how much longer we've got, give me the "heads ups" and use the same order to help me wash up. If I don't respond quickly please wait a bit longer for me.

## *Same Help in the Same Order*

1. "Let's shampoo your hair."
2. "Tilt your head back; I'll rinse your hair."
3. "Now let's wash your face."

*Continues on page three*

*Continued from page two*

4. "Let's get in your ears."
5. "Let's get under your arms."
6. "Let's wash your crotch."
7. "Let's wash your butt"
8. "And let's wash your legs."
9. (If seated), "Lift your foot and I'll wash it"

### **Same Words of Reassurance**

- "I'll be back in five minutes. It's almost time to shower!"
- "OK, we've got towels, soap and shampoo."
- "OK." We're safe. Let's go."
- "I'm going to lather up your hair."
- "Now, let's wash your face (Or crotch, or butt, or leg, etc.)"
- "Good, we're halfway done."
- "Finished! Let's get dry."

### **A Closing Word to My Helper**

My aim is not to complicate a simple thing. My aim is to have you understand that I need to know what's happening next because I hate surprises, that it's easier for both of us if we do things in pretty much the same order, that I need a lot of reassurance and that I can become confused easily. After a few times through it together it will become second nature! It'll be a piece of cake. Your job is to help me. My job is to help you help me. We'll be a well-oiled machine'

*Acknowledgement: Newsletter – December 2007 – AHDA (Qld) Inc*



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## **Personal Story**

My name is Beryl Wright and I was born in Ontario, Canada. I am a member of the Amaryllis House Advisory Group as one of the Huntington's Disease (HD) family representatives.

I was four years old when my parents returned to the UK, where I grew up and was educated. At age 17 I was working in Nottingham for the Ericsson's Company which employed 4,000 people. I was chosen to represent Ericsson's in a Business Speech Cup House Speech event, which I won and still have a replica cup on my mantelpiece more than 50 years later.

Every week I went to a local dance class and it was there I met my future husband Dennis Wright. He was the oldest of three brothers. Ultimately two out of the three would die with HD.

Dennis told me that because his father had hit his mother, he was put into a "lunatic Asylum" and no-one ever visited him.

When we had been married for two years, Dennis and I came to New Zealand, I was 20 and he was 24. Being the youngest of six daughters I think my parents were quite relieved when Dennis asked my father if he could marry me, my father didn't pause in his nightly game of Solitaire. He just shrugged and said "You can if you want".

We lived and worked in Dunedin for three years and built a house at Waldronville.

When my sister, Sheila and my brother-in-law, who came with us to New Zealand, decided to move to Paraparaumu we followed a year later.

My son was born in Wellington Hospital and two years later my daughter was born. When they were both at school, I started working at McIntosh's Pharmacy on McLean Street; I then worked for another pharmacy as the Buyer and Supervisor for three years until I had to leave to look after my husband.

For years Dennis's physical and mental health had been deteriorating. For seven years his doctor had been prescribing Valium for his nerves. In desperation, I visited the doctor myself and insisted that some tests should be done.

The result of this visit was an appointment with Mr Bergin a leading Wellington Neurologist. He contacted the Asylum where my father-in-law had died. The diagnosis was Huntington's Disease.

Mr Bergin said that in the future we would need a lot of help, just ask for it.

I was visiting my mother one afternoon in a Geriatric Unit, when I met a Social Worker, Jenny Packard. I told her that my husband had HD and that I also had two children to care for. Jenny was very interested in this because she visited a lady and her husband who also had HD. I had actually thought that I was the only person in New Zealand who was involved with HD.

*Continues on page four*

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Jenny arranged a meeting between us and when we met, it was as if a dam had burst. Someone else actually understood what I had been going through for years.

There was a meeting arranged with another lady. Her husband also had HD. Jenny then decided to put an advertisement in the paper about a meeting for HD families. Forty people turned up

We formed a committee and I was asked to be the Chairwoman, and that night the Wellington HD Association was born and three years later we became a registered Society. I was Chairwoman for the first five years.

Professor Richard Faull of Auckland was very supportive in those early years of our HD group, the first in New Zealand. He still gives his support to all the HD Associations in New Zealand. My husband's brain went to his brain bank, the largest in the world at that stage.

In the early days our HD Committee worked hard organising cake stalls, raffles and anything else that would raise some money.

I continued to look after my husband until 18 months before he died in Kenepuru Hospital.

Though I had stepped down from the chair I continued on as a member of the HD organisation.

My daughter Beverley came home from a trip to the UK. She had worked at the Social Welfare Office in Porirua since leaving college and decided to go back there. But it was obvious something was wrong. I had since met my partner David and moved to Wilton. Beverley had moved in with her brother in his house at Tawa.

It was then I met our HD Social Worker Dorothy Tortell. When she met Beverley she confirmed my worst fears, it was HD. I do not want to re-live the agonising years of her illness. When Beverley was settled into a bed sitting room in Tawa, I then went to Australia for my first holiday in ten years.

Just two days after I left New Zealand Beverley was picked up by the Police at 2.00am in Porirua. She was put into the Kenepuru Psychiatric ward for six weeks until the Circuit Judge committed her to Kimberley in Levin. He was sorry to do this, but as he explained, there just wasn't anywhere else for her to go.

My son Alvin decided to take the test.

When friends have asked me if I could say what my worst experience was, I reply I can remember quite clearly going to the Wellington Hospital to hear the result of that test. We arrived there quite early and went to the cafeteria for a cup of coffee. We talked about

everything and anything except what we were there for. Finally we could delay no longer and walked down the corridor, arms around each other to find out whether or not he had the death sentence. The answer was yes.

Fortunately my daughter Beverley was moved to a new home for the disabled in Porirua – Emmerson House. She died there in 2005 of a massive seizure. A large group of my friends and Beverley's attended the funeral at Emmerson House.

My son Alvin finally had to give up his job as a technician with Telecom. I sold my house at Paraparaumu Beach and bought another one on Moorefield Road, Johnsonville. Alvin moved in there, after selling his house at Tawa. It was so convenient for him to walk to the Mall each day for his coffee and a muffin. He gave up driving because he knew he was no longer capable or safe.

For some time the HD Committee had been lobbying Parliament for a dedicated Home for people with HD in the Wellington Region. Amaryllis House was completed in September 2004. This was a first for New Zealand and when my son became incapable of living alone he went to live, somewhat reluctantly, at Amaryllis House. The care he received there was the best.

I visited him every Monday and chaired the Residents Committee once a month for nearly two years...

I had been to a meeting of the Amaryllis House Advisory Group Meeting on Friday February 8<sup>th</sup> 2008 and decided afterwards to call in and see if Alvin was awake. He was lying in his chair in the lounge and held his arms up for hug as he usually did. He told me that he and several of the residents had been on an outing to Petone Beach and he had enjoyed it. I told him I would see him on Monday as usual then left and went home for lunch.

About 3 o'clock the phone rang, it was the manager of Amaryllis House, Margaret Simmons. She told me that a nurse had gone to Al's room to bring him for afternoon tea to the lounge. He was lying on his bed with his TV on, but his heart had stopped beating. I really went to pieces, I couldn't believe it. I adored him. Alvin's friends and mine were at the funeral, it was certainly a celebration of his life.

I do not say why me, not any more, I know why me. Every time I attend an Amaryllis House Advisory Group meeting, every time I go to Amaryllis House and every time I have lunch with friends I have made through the Association, I am reminded of the contribution I was and am able to make.

## NEWS FROM THE REGIONS

### Auckland / Northland News

Hello from Auckland and Northland. We hope you have all had time to enjoy the fantastic weather over the busy festive season.

Jane and I have both been able to have a break, and so are ready and re-energised for a fully booked and productive 2009.

Our Committee, as ever, has started the New Year with some good funding opportunities and innovative ideas which you will be informed of in the coming months.

We have got the following dates for your calendars:

The **Carers Days** for this year are

28th February, 29th August, 28th November.

The **Carers Retreat** provisional date is 16-17th May.

**Gene Positive Groups:** 15th April, 7th October

We would value your views on running "At Risk" meetings please call on free phone 0800 HDAUCK (0800 432 825)

This year the A.G.M. is on the 20th June 2009.

Due to growing numbers, these successful and informative events have moved venues please check your invitation for new addresses and contact us if you would like to be added to our mailing list.

Bye for now

*Jo and Jane*

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### Waikato News

Hello from the Waikato. I hope you had a safe and happy festive season.

I would like to take this opportunity to point out to you all that our "area" is the same as the Waikato DHB. So if you think you live in the Coromandel area or the King Country chances are I am your Huntington's contact person. I can and do travel as far south as Taumaranui and north to Whitianga so please don't hesitate to contact me if you would like some support.

The other point I would like to make is that I support

the whole family not just the person affected with HD. I know there are families in this area who have not had contact with MS Waikato in the past but situations change, so even if you have no 'problems' at present it would be nice to meet you.

My contact details are on the back cover so don't struggle on alone, pick up the phone.

I am looking forward to seeing many of you through out 2009.

*Deb Nagel*

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### Wellington News

*(Covering the following Wellington Huntington's Disease Association areas Hawkes Bay, Taranaki, Wanganui, Wellington, Wairarapa and Gisborne).*

#### Greater Wellington

Hello I am Jeanette Wiggins and I started as the advisor for HD on December 1st.

I am married with two teenage children and I come from a background of nursing that includes terminal care, rest home and hospital level care, agency nursing, public health and for a large part of my life, running a dance based fitness programme.

I was fortunate to be offered this opportunity with HD and have found the support from everybody involved has made the transition into this role very smooth.

I did get to meet with a number of families prior to Xmas and having had some prior work commitments and holidays in January, I am now back and I will endeavour to contact those that I have not already had the pleasure of meeting.

I do not work on specific days so I am available any time and would really appreciate your calls, particularly if I have yet to meet you or if you have a particular problem.

I will continue with the carers coffee group held about six weekly and I will also be involved in the fortnightly

swimming at Hutt Hospital as well as making regular visits to Amaryllis House.

I am really enjoying this new challenge, the wide range of people I am meeting and I trust that we all have a great 2009.

Kind regards

*Jeanette Wiggins*

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#### New Plymouth, Wanganui and Palmerston North

Greetings and Happy New Year to you all.

An "in-service" was organized in Taranaki at a rest home where we were joined by Jo Dysart the Auckland HD worker/Nurse Educator and her colleague Jane Devine We worked for two days together supporting families and staff at the rest home and we all felt it was a very worthwhile two days. I would like to thank Jo and Jane for sharing their knowledge and time.

Some families have requested that we start an HD support group up in the Taranaki region so this is something we hope to look into soon.

My social work services will continue to be tailored to suit the needs of each individual. I am available for home visits, telephone and email support or any other

*Continues on page six*

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enquiries. I regularly visit rest homes to visit clients but also to educate and support staff which I believe is an essential part of my job.

The Association continues to lobby for a dedicated HD house in the Wanganui Region.

Please feel free to contact me at any time should you require a home visit or any other form of support.

Kind regards

*Annette Turner-Steele*

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## **Hawkes Bay News**

Kia ora from the Bay.

Our support group continues to meet regularly for social and emotional support to families, and our new

initiatives are starting up, which include – practical support for families in particular a roster of members for visiting and spending time with people to enable their carers to have time to pursue things for themselves that they wouldn't otherwise be able to do; and regular carer mornings to enable people to get together to share stories and ideas over great coffee and cake.

I continue to meet with people and families at home visits or care facility visits, and maintain contact with people via phone calls and email - both in Hawkes Bay and in Gisborne.

Please feel free to contact me anytime for support or information.

Kind Regards

*Tanya Jeffcoat*

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## **Canterbury News**

Greetings from the south... I hope that you all had a lovely break over the Christmas period and if you didn't manage to get away, like myself, I am sure you will be looking forward to a holiday in the not too distant future.

At Christmas time, it gives us the chance to reflect over the past year, we were lucky to share our Christmas day with some very special friends and the one common thread that we all have is two very special people, my daughter Kimberley and her husband Justin.

Justin's family all came up from Invercargill and Dunedin and we spent the whole day together unwrapping presents, eating lots of yummy food, talking, laughing and sharing the day.

I talked at the conference in my closing address about the difference between "Bitter" and "Better" and how our HD journey can also leave us one of two ways, Bitter or Better.

Bitter about HD and what it is doing to our families, our children or our loved ones, or because of this disease and the way it puts things into perspective. How our HD person or family member would not want anyone that they love to feel bitter about what is happening to them or the way that the disease progresses and how it effects us that we are bitter because of it.

But Better because even for a while no matter how brief their life is or how much we go through with them and HD we are all the better for the experience and for a fleeting moment or many years they were a part of our lives and made it all the better for their existence and being part of it.

We celebrate every occasion as a family, spend as much time as possible together and are making lots of good happy memories. These memories are what will comfort us, remind us of the great times and the not so good times but will remain precious and special.

Life is what you make it, HD will take all your energy if you let it, but put it into perspective and take it one day at a time and it becomes more manageable. Day by day, week by week, this is how we cope as a family, talking

about every stage and how we can help Kimberley and support Justin through it. We do not know what is ahead, no one does but we do know that if we talk and support each other it sure makes each day and episode easier.

Our association is holding a BBQ on the 22nd February at Mary and Ashley Gilmore's house. This is a lovely way to start off the New Year and regroup and focus for 2009.

I look forward to hearing from our HD families and catching up with more of you throughout 2009

Regards Dianne Collins

*Chairperson HD Christchurch*

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My office is home and I spend a large part of my time on the telephone, answering inquiries, responding to emails and liaising with other service providers. My HD hours are 10 – 15 per week (I also work as a nurse). This year I hope to do visits on Tuesday/Wednesdays. These are the days our groups meet – 1st Wednesday even months for care support group and 2nd Tuesday each month for Recreation group.

Sometimes, there are new families who have recently received a diagnosis – what stories have they heard (on or off the internet)? HD presents differently for many people and too much information overload is difficult to get your head around. Most of the time, our HD families just try to get on with their lives – some don't want to talk about it and avoid discussion of issues – some choose denial.

I have just read an article reinforcing that HD families do face extra challenges – ghosts from the past to wonder about, secrets, decisions re testing, guilt, denial, relief and regret, but mostly unknown fears for the future.

The Carer Support Group is about families – you will be most welcome. Contact me for details or home visits at (03) 326 5189 any time.

*Lynne Switzer*  
*Field Worker*

## **Huntingtons Trust Wellington and Central North Island**

The above Trust was set up in 1993. The aim was to get enough funds to enable it to help with the day to day running of the Wellington Association and/or specific projects.

Bequests to this Trust can be made in cash, shares, real estate, or any other property and can be by way of a gift during your lifetime or can be bequeathed in your will. Bequests are free from estate duty.

If you require further information please write to:

The Chairperson of the Trust,  
P O Box 30420,  
Lower Hutt 5040



## **Mailing List**

To help us keep the mailing list as up to date as possible, could you please remember to drop us a note when you change your address. Include the name or names you want on the envelope plus your old address and new address.

If there are any mistakes that need updating, or a family member who received the newsletter has died, please let us know about them also.

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**Huntington's News** is the national Newsletter of the Huntington's Disease Associations of New Zealand. It is published quarterly (March, June, September, December) as a means of communication between the Associations and all individuals with Huntington's Disease, their families, their caregivers and professionals interested in the condition.

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- ◆ Pub Charity Inc – for assisting with projects during the year
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Many thanks to all who continue to make private donations to our Association.



## **Contributions**

Write to us about this newsletter, about information you may need, about information you may want to pass onto others. Write to us about controversial topics such as privacy, confidentiality, access, support, etc...

### ***We would like to hear from you.***

The next issue of Huntington's News will be published in June 2009. The deadline for material to be received for this issue will be 10 May 2009. Please send any contributions for Huntington's News to:

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## **IMPORTANT NOTICE:**

### ***HUNTINGTON'S NEWS and the INTERNET***

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