



# Huntington's NEWS

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

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## *Devastating News for Christchurch HD Families Due to the Earthquake*

Today I received the phone call that I was dreading. It had been nearly three weeks since Christchurch was shaken to the core by the 6.3 earthquake. It was Ron Trelease, General Manager NZCare Group (South Island) to inform me that the HD Residential Service that we have now been waiting nearly a year to open has been deferred due to the earthquake.

The service opening date, originally announced for the 1st August 2010, was changed three times and now this. To have waited nearly 30 years, a few days away from opening and then Mother Nature stepped in causing another delay.

We have been advised that there are clients in residential care with NZCare Ltd who have intellectual/physical disabilities and who are 'medically fragile' needing to have more appropriate accommodation until their homes have been repaired and are fully functional again.

This is a huge blow for our families.

It is not known when this service is going to open.

*Dianne Collins*

*Chairperson – Huntington's Disease Association (Christchurch) Inc*



# *Delay to the opening of Christchurch's new Huntington's Service*

We were on the verge of opening our new Christchurch Huntington's service in Woodham Road, when the February 22nd earthquake struck.

Although the building sustained only minor damage, the storm water and sewage systems are no longer working and we had to make the difficult but necessary decision to postpone the opening.

We are bitterly disappointed about this delay, but our vision to provide a wonderful environment for people with Huntington's to be supported in, hasn't changed.

We will be doing everything we can to have this damage repaired, so that we can provide a safe and fully operational service.

In the interim, we are supporting five people who were forced to evacuate their home – but were too frail to move out of Christchurch – to temporarily stay at the property.

This is requiring significant short-term compromises, such as the washing of clothes offsite, and the installation of a small septic tank that can cope with the minimal wastewater created by this group.

This is certainly not a sustainable option, and we will support these people to return to their own home as soon as it is declared fit for occupation.

Our priority is to have the damage at Woodham Road repaired, and to open a fantastic service for the Huntington's community, as planned.

In the meantime, we are committed to working with families to offer suitable respite options.

*Ron Trelease*

*General Manager South Island, NZCare Group Ltd*

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## *Speaking and Listening!!*

Obviously, nothing is more important in your relationship with the person for whom you're caring than communicating with one another. This becomes more and more important as it becomes more and more difficult. The movement disorder affects speech in several ways. In the mid-stages of HD, people lose precision in making sounds, control of the volume of the sounds they make, and coordination of the speech and breathing mechanisms. This creates speech that is varied in volume, interrupted by grunting or breathing sounds, and hard to understand. In the most advanced stages, people express their range of needs and emotions with a few intelligible words or sounds.

Just as the movement disorder affects speech, the cognitive disorder affects the content of what is said. The ability to form ideas, organize thoughts, and present them in an orderly sequence is compromised in HD. Some people have difficulty starting a conversation, staying on the topic, or switching from one topic to another. Some get stuck on one topic and have difficulty getting off it.

As clear speech becomes more difficult, it takes great effort for people with HD to carry on a conversation. They will have a tendency to rely on a very small vocabulary of more easily understood words. This allows you to take on a more active role in a conversation, picking up on those key words, anticipating the idea, and expanding on it on their behalf. At the point where it is extremely difficult

to be understood, some people simply stop talking. Your familiarity with a person's likes, dislikes, career, interests, hobbies, and relatives will keep the conversation going or allow you to become their "interpreter" with others.

It can be humiliating and frustrating for the person with HD, and embarrassing for you, when you have difficulty understanding their words. One way to show him respect is to put the burden of understanding firmly on you. Ask him for clarification. Ask their permission: "Do you mind if I repeat your words to you from time to time so you will know how I'm doing?"

Communication boards are commonly introduced to people who are having difficulty being understood. As well-intended as they may be, boards are not often adopted by people with HD as an alternative form of communication. Speaking, as impaired as it is, is easier than learning to use the unfamiliar board. As with other adaptive devices such as helmets and wheelchairs, introducing the communication board early, before it is actually needed, gives the user more time to learn how to use it, practice with it, grow fluent in its use, and possibly adopt it.

Some families find it helpful to assemble a book or picture album full of photographs that represent their interests, hobbies, family, career, and preferences. Since non-family caregivers may first meet the person when they

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have difficulty expressing themselves or recalling events from the past, the album serves two purposes. First, the album is a communication aid which allows them or you to point to pictures when you don't understand each other. Second, it serves as a treasury of interests, children, grandchildren, relatives, hobbies, achievements, pets, home or apartment, and favourite sports teams so you can better know who this person is and can communicate with them for years to come.

Please remember that people with HD can comprehend our speech and understand all that's going on around them to a far greater degree than most people may at first suspect. How effectively they communicate through spoken words is not an accurate predictor of how well they understand what you say.

Family members and caregivers agree that people, even in the most advanced stages of HD, somehow manage to communicate with their caregivers very effectively



through facial expressions, eye gazes, and other subtle movements that may only be understood by those closest to them.

Look and listen carefully!

### ***Caregiver Communication Tips***

#### **Have the person with HD:**

- Slow down, especially if their speech has a "racing" quality to it.
- Repeat/rephrase.
- Say the main word.
- Spell the word.
- Write the word, even if they can write only a few letters.
- Show you.

#### **You, the caregiver should:**

- Try to rephrase the main idea.
- Use short sentences.
- Ask for feedback.
- Allow plenty of time.

- Wait:– for up to a few minutes for a reply.
- Try not to repeat or rephrase a question while you're waiting for a response.
- Use touch to help keep them focused on the conversation.
- Ask for help from others when needed.
- Never pretend to understand!
- Consider using a simple communication board.

#### **The family can:**

- Make a scrapbook or memory book.
- Tell you about facial expressions or phrases that they understand.
- Continue to call or write even if they cannot respond clearly.

**Author and Editor:** Jim Pollard, MA published by the Huntington Society of Canada, 1999. Reprinted 2000.

This publication is available from the Association. If you are interested in a copy please contact email Lily at [lily@ahdansw.asn.au](mailto:lily@ahdansw.asn.au)

**From:** *A Caregiver's Handbook for Advanced-Stage Huntington Disease*

*Acknowledgement: Gateway – HDA (NSW) Summer 2011 Volume 14 No 1*

# *Huntington's Disease and Diet*

## *Why do I need to eat well?*

People with Huntington's disease can find it difficult to maintain their body weight, or they can be underweight. People who are very underweight are prone to infection, have slower wound healing and progressive muscle wasting and lethargy. People with Huntington's disease usually need a much higher calorie intake than normal.

## *I am hungry but find eating difficult*

You do not have to eat large meals. Small frequent snacks, high in calories (little and often) can be just as helpful. Do not drink large amounts of fluids with meals as these will make you feel full quickly but do try to drink plenty of fluids in between meals. Take your time over meals. Sit comfortably.

## *Add extra calories*

**MILK** is a good source of protein. Try to drink at least one pint of full cream milk a day. You can add calories easily to milk by adding 2oz skimmed milk powder to 1 pint of full fat milk.

**YOGHURT** or similar desserts can be used on fruit and puddings. Those with added cream or the thick 'n' creamy ones are ideal. Avoid low fat or diet yoghurts.

**DOUBLE CREAM** added to cereals, fruits, puddings, soups and mashed potato etc will increase calories.

**CHEESE** is a good source of both protein and calories. Full fat cheeses such as cheddar and Lancashire are the best. It can be sprinkled on creamed potatoes, soft vegetables, soups, fish in sauce, minced meats and baked beans. Add cheese to omelettes and scrambled eggs. Cheese in a sandwich, on biscuits or on toast is an excellent snack.

**MEAT AND FISH** in any form is useful. Cook well and serve with plenty of gravy or sauce. Tinned fish in oil or mayonnaise rather than brine or tomato sauce has more calories.

**LENTILS AND BEANS** are also a good protein source. They can be added to soups, casseroles, and stews, or used just as a vegetable. Baked beans on toast is a useful snack.

**NUTS** (for those who are not experiencing swallowing problems) can be added to salads, baked apples, cakes, biscuits, ice-cream and crumble toppings. They are good foods to nibble between meals. Try having a peanut butter sandwich or peanut butter on toast for a snack.

## *Foods you may find difficult to swallow*

Raw or hard cooked vegetables, salads, peas, sweetcorn, broad beans, tomato skins; hard fruits such as apples, pears, grapes, pineapples, fruit skins or fruit peel; crusty bread, pre-sliced bread, granary bread, high fibre white bread, bread crusts, toast, crackers and crisp breads; sponge cakes; crisps; hard chips; flaky and puff pastry; hard pastry crusts; nuts and food containing nuts; dried fruit and foods containing dried fruit; shredded wheat.

## *Put more energy in it!!*

**SUGAR** – use lots. Put it in hot and cold drinks, on softened cereals and in desserts.

**HONEY, JAM, MARMALADE, GOLDEN SYRUP, TREACLE** can be spread generously onto bread, biscuits and scones, if you can swallow these. Stir them into milk puddings and softened breakfast cereals. Add honey to Greek yoghurt for an excellent snack.

**CHOCOLATE** – can be melted in the microwave and added to custard, puddings or milky drinks.

## *TROUBLE SHOOTING*

### *Dry mouth*

If you find you have a dry mouth you may find the following suggestions helpful:

- small sips of drinks frequently – a small flask with a lid and straw like a cycling flask can be carried around easily.
- fruit drops may help to get the saliva flowing – some people have commented that acid drops help.
- sucking ice cubes is useful unless you are likely to swallow or choke on them. You can make these with lemonade or fruit juice as well as plain water.
- Sorbet

Ask your Doctor about the possibility of prescribing one of the artificial saliva preparations available.

### *Care of the mouth*

To keep your mouth in a healthy condition:

- use mouthwashes regularly. Ask your nurse or Doctor about the best one for you to use
- if your lips are dry, apply a lip salve e.g. Vaseline.
- clean your teeth frequently. Use dental floss.
- visit your dentist for regular check-ups.
- a cube of cheese after each meal will neutralise the acid that causes tooth decay.
- if you wear dentures, keep them clean and make sure they fit correctly. Ask your dentist for advice. Dentures are one of the first things to become loose when people lose weight.
- sometimes foods may not taste the same or seem to have no taste – good mouth care can minimise this.

### *Keeping food down*

- sit upright to eat your meals. Try not to lie flat immediately after a meal.
- eat your meals in a well ventilated room and wear comfortable clothing.
- try to ensure there is a calm, relaxed environment.
- minimise what is going on around you so you can concentrate on eating.
- discuss with your doctor or a dietician any problems regarding eating you may be having.

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### **Changing your diet to suit your need**

At times it may be necessary to avoid foods that you know cause you problems, actually identifying these can sometimes resolve the problem. Sometimes you may need to change the consistency of the food i.e. eat softer or puréed food. If you find you are having difficulty swallowing thin liquids, try thickening them slightly, this often helps and prevents coughing. There are many thickening agents on the market; your GP can prescribe one for you.

### **How to get the texture right if you need soft or puréed food**

There are three different ways to try:

#### **USING A LIQUIDIZER**

A liquidizer is the quickest and most efficient way giving the best results.

The following tips may help you:

Try not to liquidize all of the meal together, liquidize the meat and vegetables separately. You can add sauces to give flavour.

#### **MEAT AND FISH**

Remove all skin, bone and gristle from cooked meat and fish, cut into small pieces add stock or gravy or sauce to get the right consistency.

#### **VEGETABLES**

Cook them to soften before liquidizing again add stock, gravy or sauce to get the right consistency. Cooking them by steaming will maintain their nutrients.

#### **FRUIT**

It is easier to blend fruit that is soft, or thawed if frozen. Tinned fruit in syrup is a good choice. Stewed fruit can also be liquidized.

#### **USING A HAND BLENDER**

These are cheaper than liquidizers but take longer and some foods may not cooperate.

#### **USING A SIEVE AND SPOON**

After cooking some food can be forced through a sieve this may need to be done more than once.

Whichever method you use it is important to remember:

- meals need to look attractive
- all utensils should be kept clean
- meals may need warming during serving if feeding takes time.
- remember a calm relaxed environment will help!
- nutritional supplements which can help to add calories to your diet are available from your GP.
- a dietician can advise you on your individual needs. Referral can be arranged by your GP.
- a referral by your GP to a speech therapist can be helpful in resolving some of your swallowing problems.

### **Some ideas for soft and puréed diet**

#### **DRINKS**

##### **FORTIFIED MILK**

1 pint of milk (full fat)

Glucose powder

Put the powder into a jug. Add the milk gradually, stirring all the time until all the powder has dissolved. Store in the fridge.

##### **HONEY CUP**

½ pint fortified milk

2 tsp honey

Warm the milk. Put the honey into a cup. Pour the warm milk into the cup, stirring well.

##### **MILK SHAKE**

½ pint fortified milk

1 scoop ice cream

Milk Shake flavouring

Stir all the ingredients together in a tall glass

##### **YOGHURT FLIP**

½ pint fortified milk

1 carton of ordinary fruit yoghurt

Sugar to taste

Whisk all the ingredients together in a tall glass, serve chilled.

##### **MINT CHOCOLATE COOLER**

½ pint fortified milk

2 - 4 heaped tsp drinking chocolate

Peppermint flavouring

Grated chocolate

Mix the drinking chocolate and the peppermint flavouring with a little milk. Add the remainder of the milk, stirring well. Pour into a glass and decorate with grated chocolate.

##### **CITRUS SURPRISE**

½ pint fortified milk

Lime cordial

Orange and lemon slices for decoration

Add milk to the lime cordial according to taste. Serve chilled in a tall glass decorated with orange and lemon slices.

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### **WHISKY AND HONEY WARMER**

$\frac{3}{4}$  cup of warm milk  
2 level teaspoons clear honey  
1 tablespoon whisky or brandy  
Warm the milk, stir in honey, pour into a cup.

### **HOT MILK MOCHA**

$\frac{1}{2}$  pint of milk  
2 tablespoons drinking chocolate  
1 level teaspoon instant coffee  
1 tablespoon double cream.  
Boil milk and pour into mugs, add chocolate and coffee, stir well, swirl in fresh cream and serve.

There are a wide range of high calorie, high protein drinks in many sweet and savoury flavours available from your GP or contact your Dietician.

### ***Meal ideas for those who have difficulty swallowing***

#### ***Breakfast***

Porridge  
Instant hot oat cereal  
Weetbix  
fruit juice  
puréed fruit  
plain or flavoured yoghurts

#### ***Main Meals***

soup  
casseroles, hotpots etc  
fish with sauces  
pasta dishes  
cauliflower cheese  
cheesy potato bake  
lentil bake

#### ***Puddings***

puréed fruit  
milk puddings e.g. rice puddings,  
semolina, custard, blancmange  
jelly, including milk jelly  
smooth yoghurts and fromage frais  
ice cream and sorbet  
instant puddings, egg custards and crème caramel

NB: TRY TO HAVE A GLASS OF FRESH ORANGE OR GRAPEFRUIT JUICE OR BLACKCURRANT CORDIAL EVERY DAY TO PROVIDE YOU WITH SOME VITAMIN C.

A Dietician can give you detailed individual advice about your needs. A referral can be made via your GP. The Huntington's Disease Association has a team of Regional Care Advisers who can offer help on a wide range of problems.

### ***Fact sheets available from the HDA (UK):***

Email: [info@hda.org.uk](mailto:info@hda.org.uk) Web: [www.hda.org.uk](http://www.hda.org.uk)

- General Information about Huntington's Disease and the HDA
- Predictive Testing for Huntington's Disease
- Talking to Children about Huntington's Disease
- Information for Teenagers
- Eating and Swallowing Difficulties
- Huntington's Disease and Diet
- The Importance of Dental Care
- Communication Skills
- Behavioural Problems
- Sexual Problems
- Huntington's Disease and the Law
- Huntington's Disease and Driving
- Advice on Life Assurance, Pensions, Mortgages etc
- Seating, Equipment and Adaptations
- Checklist for Choosing a Care Home
- Advance Decision to Refuse Treatment (ADRT)
- A Carer's Guide
- Challenging Behaviour in Juvenile Huntington's Disease
- A Brief Guide to Juvenile Huntington's Disease for Children's Hospices and Palliative Care Service
- A Young Person with Juvenile Huntington's Disease at School

All Fact sheets can be downloaded for free from our website: [www.hda.org.uk](http://www.hda.org.uk)

*Acknowledgement: Huntington's Disease Association (UK)*

## Auckland / Northland News

HD Auckland is very proud to announce an incredible few months of fundraising success.

### HD Charity Dinner

On the night of what should have been her wedding day, Leanne Knox helped us to raise \$32,800 for people with Huntington's disease. Leanne's mum has HD, and this spurred the 25 year old to turn her engagement disappointment into a fundraising dinner. All proceeds of the night, held in November at Butterfly Creek Wildlife Park, were split between the Huntington's Auckland Association and Multiple Sclerosis Waikato.

A surprise donation of \$20,000 on the night from the Remuera Lions Club saw the total sky rocket. The donation has been used to buy a new car for our family liaison officers Jo Dysart and Jane Devine.

Mark Dunlop, the Chairman of the Huntington's Auckland Association, said, "Funding has been tough for us lately with the global financial crisis, so this donation is an incredible boost. A new car means that our dedicated workers can get out all over Auckland and Northland to visit people who need our help. Leanne is really an extraordinary woman to do this for us, and we are just so grateful."

Leanne, who has been tested for the HD gene and doesn't have the disease, said, "While it was sad for my relationship to end, I knew I could turn this around into something special for other people. I'm just so grateful for all the donations on the night; I couldn't believe it when I saw the final amount we raised! It's just so special that everyone came together to make a difference."



The Lions Club of Remuera present their amazing donation of \$20,000 for a new car

Our HD committee organised the dinner in just six weeks, calling in much help from family and friends! The dinner was a sell-out, with all 120 seats sold. Donations flooded in from dinner guests, including sizeable donations from the Freemasons Roskill Foundation as well as the Lions Clubs of Cambridge and Tokoroa Host. Items donated to the charity auction included bach holidays, cases of wine, a shirt signed by All Black Tana Umanga and a tour of the Centre for Brain Research at The University of Auckland.

Guest speakers included neuroscientist Professor Richard Faull and The Baby Factory founder Gordon Lowe. The star guest on the night was Silver Fern Temepara George who was interviewed by former Northern Force Manager and family friend Debra Charteris. Temepara spoke about her Commonwealth Games gold medal successes and the highs and lows of her career in netball. She also kindly donated a Silver Fern history book for auction and a highly fought over Ferns dress!



Leanne Knox with Silver Fern player Temepara George



The charity dinner was packed out.

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"I'd just like to thank everyone for their help in putting this event together," says Leanne, "I know the funds will make a real difference to my mother, my family and others like us."

### **Sausage Sizzles**

Our team has also been hard at work over the last few months fundraising in less glamorous circumstances! Christine Stent has been organising sausage sizzles and collections across Auckland, including the Mad Butcher chain and St Lukes Shopping Mall. The team has managed to raise over \$850, which will all go towards helping families with HD.

### **Helpers needed!**

We are pleased to announce a new member of our committee. Trevor Lowe is joining the team as Treasurer, and has been busily working to bank our fundraising successes.



*Temepara George speaking on the night with Northern Force manager Debra Charteris on the left*

However the team is in need of more help from our community. We need more committee members, as well as more volunteers to help us fundraise and organise vital networking events for HD families.

If you would like to join the committee, or help at our next event, please email [huntingtonsakld@xtra.co.nz](mailto:huntingtonsakld@xtra.co.nz)

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## **Waikato News**

Kia ora whanau – Wow we're into March/April already, the weather is starting to cool off and there's that nip in the air that tells us autumn is just around the corner.

It has been fairly quiet here client wise since Christmas, which apparently is to be expected, and for me personally well this is another story, I have increased my hours to full time for the next four months, to support my manager whilst she is on placement, so I will be doing a lot more MS Support whilst continuing to support my families with HD, and continue with my own personal studies, I look forward to this challenge.

The MS Waikato exercise program is back in full swing and over the past three - four months I have been able to introduce a few more people with Huntington's to this group, they are now going along religiously. As well as the physical exercise they are participating in, they also receive the social interaction with a variety of people with varying disabilities, and I am noticing small, positive changes, which is great to see.

I would like to say a big Thank You to all the HD fieldworkers who took the time to respond to my email informing me of the types of support groups that are being run in their areas, this was extremely helpful. I have since then organised my first official support group meeting for my HD Clientele and Families, which was held on the 12th March, to establish what their ideas and thoughts are regarding support groups and education sessions, as there has not been anything organised for the past couple of years. I will have more details after this date.

I can always be contacted on DDI: 07 834 4745, mobile: 027 3855425, email: [tracy@mswaikato.org.nz](mailto:tracy@mswaikato.org.nz) should you wish to discuss anything with me.

Hei Konei rà – Farewell until next time

*Tracy Hobbs*

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### **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



# Wellington News

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

## Greater Wellington

Hi Everyone, March already and we are well into another busy year.

On the 19th March I attended the Wellington Brain Day and provided information to the public about HD and attended some of the very interesting lectures that were on offer.

The year has started with a number of new referrals and some challenging situations with clients and I am working with a number of other health professionals to provide the best solutions possible for my clients.

There have been some great new initiatives at Amaryllis House under Hilly Lutter, the new Service Manager, and I continue to support families there. I have negotiated a discounted price for the residents at a local boutique movie theatre which will enable the residents to make regular trips and watch in comfort. They have also reinstated a monthly happy hour, which both residents and staff enjoy.

We are back at the Hutt Hospital Pool on a weekly basis, which means that Amaryllis residents can come on a rostered basis, which they really enjoy.

A couple of weeks ago, I took two very generous clients to Wellington Hospital to answer questions about Huntington's for groups of 4th year medical students. This was a very valuable resource for the students but

a very tiring one for the people involved as it meant a constant rotation of groups for the afternoon. I am sure that the students will now have a very clear understanding of HD and the multiple difficulties involved.

The International Conference is in Melbourne in September and I am hoping to be able to attend and get up to date with the latest in research and treatment worldwide as well as networking with other HD advisors.

Our clients continue to use Noel Hamilton House in Greytown and Spring Lodge in Upper Hutt for respite care and we have transferred a displaced Christchurch client to Spring Lodge. We are grateful to both facilities for their support for our clients and their interest in upskilling their staff in the specific care for HD.

Apart from the distress to all of Christchurch regarding the earthquake, we were very sorry that the new care facility could not open on March 1st and we convey to all HD families in Canterbury our best wishes and hope that the facility will be back on track as soon as possible.

I hope I have managed to make contact with all families in the Wellington area but if you require support or I have not met you yet, please call or text on 021 344445.

Kind regards

*Jeanette Wiggins*

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## Taranaki, Whanganui and Palmerston North

Wow it's March already!

It's true the old saying 'the older you are the faster time goes by'.

With each passing year medical practitioners are getting better at recognizing the symptoms of Huntington's disease, leading to more and more people being referred for testing, resulting in new Huntington's families. Every month and sometimes every week there is another family given the news that a member of their family has Huntington's Disease and the implications that come with that knowledge.

With families coming to terms with Huntington's Disease, there is a need for people to talk to, gain an insight into where to from here, be that a support group

or a discussion with the local Huntington's advisor. If you would like to be part of a support group, would like some information (for you, a family member or an employer) please let me know and I will see what I can do to help.

My Contact details have changed

Contact number is now (06) 213 0307

Cell no is the same (027) 496 6500

PO BOX 20

Waverley 4510

Make the most of the warm weather and again if you want to contact me just give me a call or send an email.

Kind regards

*Fleur Brett*

## *Hawkes Bay News*

Kia ora koutou.

Kind thoughts to you all, especially those personally affected by the tragedy in Christchurch.

Here in Hawkes Bay our families continue to meet together and offer mutual support and friendship.

I meet regularly with all families, and am encouraging everyone to take up our relaxation massage which is provided low-cost by some special therapists and the cost is covered by group funds.

I also meet with the rest home nursing managers where some of our people with HD are living and ensure that

staff are well resourced and informed to provide best care.

Our Carers Retreat will finally take place this April – providing a welcome and well-deserved break and treat for a few of our carers.

Please feel free to contact me for a chat or to make a time to catch up.

Kia kaha

*Tanya Jeffcoat*

*ph (06) 8353020*

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## *Christchurch News*

Greetings from Christchurch.....As I sit and write to you all we are still experiencing many after shocks. My poodle Libby staying close by me when I am home and her letting me know one is on it's way as she starts shaking, before it gets to us. The total now since the September 4th Earthquake is 4879 and no end in sight.

Well a lot has and has not happened since the last magazine. The Christchurch Association was gearing up and looking forward to the opening of the new residential service for people with HD and other neurological disorders. The demand for this service was even more after the plight of some of our HD family members was brought to our attention after the September 4th Earthquake. The need for this service became more apparent and we had people hanging on and being cared for in temporary accommodation waiting for this service to open.

The opening was meant to have happened just before Christmas but the date was put out to 1st March 2011 as it was apparent that the revised Fire Regulations that were now being enforced on the building were not going to be completed in time. Everything was full steam ahead until the 22nd February when Christchurch was hit yet again with another Earthquake.

The new service is in one of the areas in Christchurch that was affected badly by the quake. It became apparent that the damage to the house was going to put the opening of this service back yet again.

This is very disheartening and just adds to the reality that everyone is being affected by these aftershocks in many different ways.

A new date has not been set yet for the opening of this service because now it becomes a waiting game as we wait for assessors to start the process all over again in Christchurch.

The 11 television's that were purchased for the house by the Association are all safe and sound, they had not been installed yet and are still in the packaging that they came in.

The loss of life in Christchurch is devastating and there are not many people who don't know someone that has lost a loved one.

Homes have been destroyed, jobs have been lost, people are dazed by what has happened and the magnitude of it all is almost too much to comprehend. For most of us holding it all together for family and friends will be harder once the reality of seeing our beautiful city in the crumbling mess that it is, over the weeks ahead.

My son-in-law, Justin is in the Territorial's and has just finished a nine day stint in the CBD. I am so proud of the way he responded to the needs of others at this time. His wife, our daughter Kimberley moved in with us so that we could take over her care so that he was able to do this. For me as a mother it was comforting to know that my family, were all together under one roof. The after shocks never worried Kimberley and she was quite happy to be with us. The daily routine that Kimberley was used to changed often as things cropped up and both Dave and myself had to juggle work and care for her. Our other daughter Katie was a wonderful part of the team that we formed to make sure that care was in place for Kimberley. As soon as it was possible, her usual carer Debbie was back filling in the daytime slots; this was great team work and while things were so hectic it gave us a different focus at home.

I thank all the HD members around New Zealand who have been in touch sending us their prayers and thoughts; it is comforting to know that we are in your thoughts at this time and that you have taken the time to convey this.

I hope that by the next news letter that I may have some news of the services opening date, until then take care and stay safe.

Kind regards

*Dianne Collins*

## ***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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## ***Thank you To Our Funders***

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- ◆ The Thomas George Macarthy Trust for their support in the production of this Newsletter
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Many thanks to all who continue to make private donations to our Association.



*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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## ***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 August 2011. The deadline for material to be received for this issue will be 10 July 2011. Please send any contributions for Huntington's News to:

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## ***IMPORTANT NOTICE:***

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

Please note that any article published in Huntington's News may be selected for reproduction on the INTERNET on the "Huntington's Disease Scene in New Zealand" website [www.huntingtons.org.nz](http://www.huntingtons.org.nz)  
If you are submitting an article for the national newsletter, please indicate to the editor if you prefer your article not to be reproduced on this site.

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