

JOINT SUPPORT

ARTHRITIS NEW ZEALAND NEWSLETTER MARCH 2018



Improving the life of every person affected by arthritis

“You’ve changed our lives”



Sophie, Julia and Tasmyn enjoy the foam slide.

Twenty-five children with arthritis and their parents had a wonderful time at our Children’s Camp last month.

One of the major benefits is that families can meet with others and share their experience of living with arthritis. “I’m not alone anymore,” said one parent.

Some of the children, aged from 6 years to 14 years, had never met another child their age with arthritis and were still coming to terms with its effects. Most had been diagnosed with arthritis in the last two years and their parents talked about the shock of being told their child has a condition normally associated with old age. They shared a range of emotions –

bewilderment, denial, anger, and most of all, wondering why.

There is no known cause for arthritis in children but the condition doesn’t need to hold children back or mean they have to abandon their dreams; it just means rethinking how to realise those dreams.

The annual camp combines learning sessions for children and parents with lots of fun and the opportunity to make new friends and spend time together.

The youth leaders and teenagers who have grown up with arthritis played a valuable role at camp. They talked to parents about what it was like for them, and provided fantastic role models for the children.

“Thank you Arthritis New Zealand,” said one parent. “You’ve changed our lives.”



**ARTHRITIS
NEW ZEALAND**

KAIPONAPONA AOTEAROA

Arthritis at a glance

Around 647,000 adults are now living with arthritis according to latest Ministry of Health figures, up from 624,000 in 2016.

New Zealand Health Survey data published in December shows half of all adults over 75 have arthritis. Forty-nine percent of all those with arthritis are of working age. Numbers will continue to rise as the population ages, placing even more of a burden on the health system.

At Arthritis New Zealand, we see the impact of arthritis daily, as you can see from our latest fact sheet below.

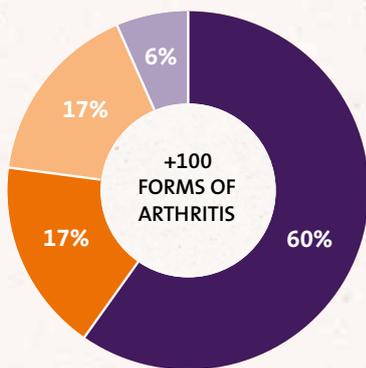
Every year arthritis costs New Zealand an estimated **\$3.2 billion**

647,000+

Kiwis are affected by arthritis.

49% are of working age.

Women are more affected by arthritis than men.



- Osteoarthritis** 386,000
- Gout** 110,000
- Rheumatoid arthritis** 109,000
- Other** 42,000

The numbers are rising



ARTHRITIS is one of the leading causes of disability

GOUT

- Gout is the second most common form of arthritis
- Gout is more common in New Zealand than in any other country
- Māori and Pacific people are more likely to have gout than other ethnicities, due to genetic factors

- Arthritis as a health priority
- Access to rheumatology services and medications
- Accessible packaging
- Early treatment of gout
- Barriers to paid employment

TOP 5 ISSUES

30,000 people use our education, information and support services

298,243

WEBSITE PAGE VIEWS

4,600

FACEBOOK & TWITTER FOLLOWERS

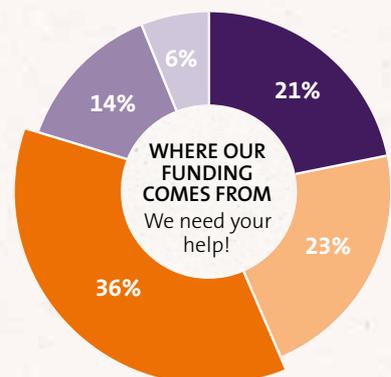
10,000

VOLUNTEERS AND SUPPORTERS IN LOCAL COMMUNITIES



84 children have attended our annual Children's Camp

1/3 of our clients are Māori or Pacific



- Health contracts
- Sponsorship and grants
- Fundraising - donations, bequests, appeals
- Investments
- Other

A wonderful time at camp



About 90 people attended camp altogether.



"It's wonderful!"

Ilah and her mother Larissa enjoy the river



"So great to be a part of this camp."



"Camp is awesome."



Tasmyn had a message for everyone after camp:



A group of children spends time with occupational therapist Clare Roberts.



Arthritis New Zealand would like to thank the volunteer leaders, youth leaders, members of the National Paediatric Rheumatology team, and KWANZ (Kids with Arthritis NZ) for their support.

Gardening with arthritis

People with arthritis often ask, “Do I have to give up gardening now?” The answer is no! By making just a few adjustments to protect your body from undue stress and fatigue, you can still get out and enjoy your garden.

The good of gardening

Gardening is an excellent way to keep physically active and maintain your quality of life. Regular gardening can help reduce stress, fatigue and blood pressure. It improves blood circulation, mood and sleep, slows bone loss, and helps you maintain a healthy weight.

Gardening is a great activity for arthritis as it keeps joints flexible and strengthens muscles and bones. Being outside in the sunshine provides Vitamin D, which helps your body absorb the calcium it needs to keep your bones strong.

Caring for the gardener

You may need to change the way you work in the garden in order to protect your joints. Repetitive actions can lead to swelling and pain so aim to exercise joints and muscles without straining them. It helps to pace yourself – know your limits, change tasks often, and rest when you need to.

Tips for protecting your joints

- Use your strongest joints – when carrying something, take the weight through your forearm rather than hands and fingers
- Don't stretch too far – work within easy reach and keep objects close to your body as you lift them
- Use light, ergonomic tools that are easy to control
- To lift, always bend from the knees and use your leg muscles, not your back
- Avoid pinching, squeezing or twisting movements.



Begin and end your gardening session by stretching. This will make your muscles more flexible and help prevent stiffness and soreness afterwards.

Make it easy

When thinking about your garden, consider:

- planting shrubs or perennials that bloom every year, so you don't have to replant each time
- using mulch to reduce the need to water
- gardening when the soil is moist as the ground will be softer
- planting in hanging baskets or pots
- raised gardens to minimise stooping and kneeling.

Painful joints and weak muscles can make gardening a challenge. But by changing just a few things and taking it slowly, you can do yourself a power of good and still enjoy the fruits of your labours.

Helpful gadgets and gizmos

See your local hardware store, gardening centre or disability equipment centre for arthritis-friendly tools and gardening aids, such as:

- An old stool or a padded kneeler that saves standing
- A wrist splint or thumb splint for weak wrists and fingers
- A carpenter's apron with several pockets for carrying small tools
- Ratcheting pruners and loppers which require less strength
- An old golf cart, wagon or wheelbarrow for carting tools, pots or loads of rubbish
- A moveable reel to store your garden hose.

Safety checklist

- An up-to-date tetanus vaccination
- A mask to wear when handling compost or soil mix to prevent infection from Legionella bacteria
- Sun protection.



Whanganui garden amble

Wet weather on 22 January did not dampen the enthusiasm of the Whanganui arthritis volunteer group who organised their 16th garden amble this year.

Led by David Orr, the team hosted visitors to 10 gardens around the city. About 200 people braved the rain to enjoy stalls, raffles and refreshments along with the blooms. Funds raised from the event will be used to promote arthritis activities in Whanganui.



Committee members Liz Robertson (left), Maureen Govenlock (centre) and Chair David Orr

Milk bottles are hardest to open

Milk bottles top the list of hard-to-open packaging, according to our recent survey of people with arthritis.

About a third of those who completed the survey said they struggled with the pull-tab seals on milk bottles, either because the tab wasn't big enough or



they had lost grip and strength in their hands.

Childproof lids that require a squeeze or push and turn action also caused problems for many, as did blister packs and pull tabs on cans. Other forms of difficult packaging are:

- packets with glued or hard to grip seals
- products encased in hard plastic
- oil wrapping
- jars with tight lids.

People asked for easy-tear perforations and clearly marked instructions. They also said bigger pull tabs, less glue, and more screw top lids would be helpful. Some identified specific tools they use to open packaging, such as jar keys, electric can openers, non-slip mats, or nutcrackers. More than 60 percent had someone at

home who helped them open packaging.

A total of 204 people responded to the survey. They noted a wide range of products (214 unique items) that were difficult to open and 50 that were easy to open. Full survey results are at www.arthritis.org.nz/surveys/packaging-survey-results/

Arthritis New Zealand is now working with the Packaging Council and packaging companies to address the issue of accessibility on behalf of people with arthritis.



National plan needed for osteoarthritis care

A group of academics is calling for coordinated osteoarthritis management and care to be recognised as a priority in New Zealand and delivered nationwide.

The group, which includes our President Peter Larmer, says a model of care for osteoarthritis would save money and improve quality of life for many. Rather than waiting for expensive surgery, patients could be informed about other options and actively involved in their management, including exercise, diet and pain-relief.

At present, osteoarthritis care is fragmented, with little collaboration

between health providers and a lack of regional consistency. The Ministry of Health's Mobility Action Programme (MAP) is a step in the right direction by funding support programmes in local communities for people with long-term musculoskeletal conditions. While yet to be evaluated, MAP could be upscaled to form the basis of a more effective model of osteoarthritis care that focuses on collaboration and prevention.

The case studies below highlight the benefits of such a system. Agnes and Bill are not real people but they both have osteoarthritis. Agnes' story is typical of how the condition is treated and managed under our current health system. Bill's experience is what could happen if a comprehensive model of care for osteoarthritis was adopted in New Zealand.

Agnes: The current system



Agnes, 66, has knee pain which has been getting worse in the last 12 months. She now has trouble walking up and down

stairs and doing household chores. Since she retired she's been caring for her young grandchildren two days a week while her daughter works, but lately this has become difficult. She stopped playing social tennis several months ago and hasn't been getting out to visit her friends. As a result, she is becoming more isolated and is showing signs of depression.

Agnes saw her GP six months ago, when an X-ray showed she had moderate osteoarthritis in both knees. Her weight

gain means she is now classified as obese. The GP prescribed pain-relieving medication and anti-inflammatories. She also talked to Agnes about weight-loss and exercise but did not refer Agnes to any other health professionals.

Agnes may have to wait six months to see an orthopaedic surgeon. She feels that, soon, she won't be able to care for her grandchildren. Agnes is very anxious and feels her quality of life is deteriorating.

Bill: With a model of care in place

Bill is 61 years old. The pain in his left hip is getting worse and he limps quite badly, especially on busy days. He took up jogging to try and lose weight but stopped when exercise made the pain worse. He works part-time but fears he may have to retire earlier than planned.

A physiotherapist assessed Bill thoroughly and told him he might have osteoarthritis; an X-ray ordered by his GP confirmed this diagnosis. The physiotherapist then suggested a programme that would

help Bill manage his symptoms. They developed a care plan together and discussed options apart from surgery and drugs.

Bill joined an exercise group to focus on strengthening his hip. He was referred to a pharmacist for pain medication, a physiologist for a general exercise plan, and a dietician for advice on healthy eating. Bill was happy to hear that all these services would be partially funded by his local district health board.

Six weeks on, Bill can walk for half an

hour three times a week, mostly without limping. He has lost 3kg and feels healthier and stronger. Since he's happy with his progress, he's decided not to see an orthopaedic surgeon for now. Bill feels able to continue his exercise and diet regime on his own, confident that good advice and care is at hand if he needs it.



The pain went on for years...

Marlene endured the pain of rheumatoid arthritis for ten years, with no one to turn to for support.

Diagnosed in her mid-20s, she found the following decade mentally and physically exhausting. "I felt pretty miserable. Sometimes I felt so ill that even breathing hurt because of the inflammation in my ribs," she says.

Everyday tasks were a struggle, especially with two young children to look after. Marlene felt friends and family might think she was "just moaning" if she said anything about the constant pain. There was nobody to talk to who empathised.

That was 50 years ago. Life changed for Marlene when she came into contact with Arthritis New Zealand. She discovered a large network of people living with arthritis, and health professionals who were able to offer advice and give the

support she so desperately needed.

Today, Marlene is still passionate about our work because she knows first-hand what a difference it makes. She's keen to let others know about the help available through our 0800 number, advocacy campaigns and arthritis educator services.

"It's so important to ask questions if you're showing symptoms. Realise that help is there, and always ask!"

Please consider making a gift today so we can reach others like Marlene with life-changing advice and support. Phone **0800 663 463** or use the coupon on page 11.



Giving for good

We recently joined The Good Registry which encourages people to make gifts to good causes instead of buying birthday, wedding or Christmas presents. One lovely woman posted this story:



"I am looking forward to celebrating my 50th birthday with my lovely friends and family here in Dunedin. I have chosen Arthritis New Zealand because I have three close friends and some dearly loved parishioners whose lives have been severely affected by arthritis or ankylosing spondylitis. One of them told me, "Every time I see my consultant, I walk in secretly hoping he's going to say, 'Good news - we've found a cure!' It hasn't happened yet. Still, I keep hoping that one day..."

"In contrast, I have had a wonderful first 50 years, and I'm looking forward to many more. I really don't need any gifts that can be wrapped up, but I love the idea of helping to raise money to transform and improve the lives of so many people here in Aotearoa New Zealand."

To support Arthritis New Zealand on your birthday or other celebrations, go to www.thegoodregistry.com

Arthritis New Zealand is grateful to be supported by:



Out and about at summer events

Our arthritis educators and other staff have been busy around the country with various events and expos.

On Waitangi Day, Georgia Grant-Mackie was busy at a stall near the Treaty Grounds, conducting uric acid testing and raising awareness about gout. She was joined by Stuart Selkirk, gout kaiāwhina from Manaia PHO, who is taking over the gout follow up work in Northland.

Jane Messer was also in Northland in December, representing Arthritis New Zealand at the Tiaho Trust's bi-annual Getting Out There – Making

the Most of Living Expo where she was enthusiastically supported by members of the Whangarei Support Group.

In Taranaki, Lettie Neri-Isele spoke to a number of groups about arthritis and attended the Taranaki Pasifika Day.

Wellington staff turned out to Te Rā O Te Raukura cultural festival in Lower Hutt where Arthritis New Zealand was part of the warrant of fitness tent, providing health and screening advice.



Georgia (centre) at Waitangi with Stuart Selkirk and a nurse from Healthline (left)



Lettie with members of the New Plymouth Arthritis Support Group.

Becoming a charitable trust

Our AGM last November voted to change Arthritis New Zealand's legal status from an incorporated society to a charitable trust. What does this mean for the organisation?

Firstly:

- services and activities will operate as they do now
- support groups will not be affected
- we will continue to fundraise to keep our services going
- we will strengthen our connections with support and other local groups.

One significant change is that we will no longer have financial members as they are not required in a charitable trust structure. Instead, all our current members will be offered the opportunity to become friends of Arthritis New Zealand. The new trust will also be able to recognise those who have made a significant contribution as Honorary Life Friends of Arthritis New Zealand.

Under the new legal structure our Governing Body will become trustees and our legal entity will be the Arthritis New Zealand Charitable Trust. If you would like to read the full Trust Deed, it is available on our website or you can call us on 0800 663 463 and ask for a copy to be posted to you.

We do want to keep in touch with our current members and supporters and we value your feedback on our communications. As part of this, please complete the Joint Support reader survey either via our website or by filling out the form on the following pages and returning it to us in the reply paid envelope enclosed. Thank you for your ongoing support.

Peter Larmer
President



What do you think of Joint Support?

We are running a survey to ask for your feedback on our quarterly magazine, Joint Support. You can fill out the survey online at www.arthritis.org.nz/surveys or complete the form below and return it in the enclosed reply paid envelope to Arthritis New Zealand, PO Box 10020, Wellington 6143.

Thank you!

1. How much time do you spend reading Joint Support in total?

5-15 minutes 15-30 minutes 30-60 minutes 1-2 hours 2 hours or more

2. How do you usually read Joint Support?

All of it at one time All of it over a period of time Only the articles that interest me

3. Do you find Joint Support easy to read in terms of print size and colour?

Yes No If no, what would make it easier for you to read? (Please comment below)

4. What topics do you think should be in Joint Support? (Please tick the rate that applies)

Information about our services	<input type="checkbox"/> More	<input type="checkbox"/> Same	<input type="checkbox"/> Less
Information about upcoming events	<input type="checkbox"/> More	<input type="checkbox"/> Same	<input type="checkbox"/> Less
Stories about people who have arthritis	<input type="checkbox"/> More	<input type="checkbox"/> Same	<input type="checkbox"/> Less
Organisational matters	<input type="checkbox"/> More	<input type="checkbox"/> Same	<input type="checkbox"/> Less
Information about our fundraising	<input type="checkbox"/> More	<input type="checkbox"/> Same	<input type="checkbox"/> Less
Medication information	<input type="checkbox"/> More	<input type="checkbox"/> Same	<input type="checkbox"/> Less
Product information	<input type="checkbox"/> More	<input type="checkbox"/> Same	<input type="checkbox"/> Less
Latest research	<input type="checkbox"/> More	<input type="checkbox"/> Same	<input type="checkbox"/> Less
Advocacy issues	<input type="checkbox"/> More	<input type="checkbox"/> Same	<input type="checkbox"/> Less
Health sector information	<input type="checkbox"/> More	<input type="checkbox"/> Same	<input type="checkbox"/> Less
Other (please state below)	<input type="checkbox"/> More	<input type="checkbox"/> Same	<input type="checkbox"/> Less

5. Please rate the articles you read from 1 to 5 (Tick the number that applies, where 5 is excellent, 4 is good, 3 is average, 2 is below average, 1 is of no value)

Information about our services	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Stories about people with arthritis	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Fundraising activities	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Advocacy issues, e.g. packaging, health policy	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
How to manage arthritis	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Arthritis New Zealand activities and services	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
President's and CE's reports	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Research	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Snippets from around the world	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Articles about pain management	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Exercise tips	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Diet and nutrition	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1

6. Which articles are the most relevant to you personally?

7. What new features or other information would you like to see in future issues of Joint Support?

Please continue overleaf...



What do you think of Joint Support? Continued

8. Do you read Joint Support online? Yes No If yes, what device do you use to read Joint Support online?
 Computer or laptop Tablet Smartphone

9. How would you prefer to receive Joint Support?
 Posted as a magazine Emailed as a pdf Email link to the website version

10. How often do you visit our website www.arthritis.org.nz?
 Once a day or more Two or three times a week Once a week Less than once a month Very occasionally/Never

11. What is your experience of or interest in arthritis?
 I have arthritis I care for a child with arthritis I care for an older person with arthritis
 I am interested in arthritis but neither I nor my family member has arthritis

12. What kind of arthritis do you or your family member have? (Please tick all that apply)
 Osteoarthritis Ankylosing spondylitis Lupus
 Gout JIA Scleroderma
 Rheumatoid arthritis Polymyalgia rheumatica Sjögrens syndrome
 Fibromyalgia Psoriatic arthritis I/We do not have arthritis
 Other (Please specify) _____

13. How old are you? under 25 25-34 35-44 45-54 55-64 65-74 75-84 85+

14. Do you have any other feedback about Joint Support?

Thank you for taking the time to complete our survey.



Gout research wins top prize

University of Otago rheumatologist Professor Lisa Stamp has won a top national prize for research into effective use of gout medication to improve patients' lives.

Gout is the second most common form of arthritis in New Zealand and is twice as likely to affect Māori and Pacific patients as any other ethnic group. Professor Stamp and her team demonstrated that increased doses of allopurinol could be given safely without undue side effects to prevent ongoing attacks of the painful disease.

The Medicines New Zealand Value of Medicines Award came with a \$20,000 prize that Professor Stamp will use for further research on patient responses to allopurinol.

MOA enrolments

Enrolments are still open for an online support programme for people with osteoarthritis. MOA (short for Managing OsteoArthritis) was developed by Arthritis New Zealand and Melon Health and is being piloted in five DHB areas with support from the Ministry of Health.

Feedback from users has been positive, with many finding new motivation and a sense of community through the programme. One man said, "There's so much to like about MOA. My coaches and the people in MOA are inspirations to helping me with my arthritis. My personal goals are to understand more about my body and how I can look after it. It's not too late to start – it's never too late to start."



Giving was a way of life for bequest donor

A Lower Hutt man who quietly donated to numerous charities throughout his life has done the same in death – leaving gifts to ten charities, including \$100,000 to Arthritis New Zealand.

Thomas Graham worked as an engine driver and collected scrap metal for sale. He had no immediate family, lived a frugal life and gave to 23 charities every month.

In his later years, his health deteriorated and he had arthritis in his hip, but was told he would have to wait some months for a joint replacement. By the time his godson had convinced him that he could afford private surgery, other health issues prevented it from going ahead.

News of the bequest came as a complete surprise to our Philanthropy Manager, Dianne Armstrong.

"I wasn't sure whether to believe it at first but of course I was delighted with the good news. Bequests like these are treasured gifts that make a huge

difference, well beyond a donor's lifetime," she said.

Mr Graham's bequest was tagged for capital expenditure. It will be used to upgrade our IT system and teleconferencing hardware, and to refit the Wellington office to create a meeting room and quiet spaces for our arthritis educators to respond to 0800 calls.

Leaving a bequest to Arthritis New Zealand is a good way to ensure the cause you support can continue to improve the life of every person affected by arthritis. It's simple and easy to include us in your Will and any such gift, large or small, is greatly appreciated. To find out more, please contact: Dianne Armstrong on **0800 663 463** or email **Dianne.armstrong@arthritis.org.nz**



Tax credit for donations

Did you know you are entitled to a tax credit for donations to Arthritis New Zealand? This is a refund of one third of any donation over \$5. This means a donation of \$100 towards our work entitles you to a \$33.33 tax credit. To claim the refund, all you need to do is file an IR526 form after 31 March and provide your donation receipts. You can even donate your tax credit back to us and be rewarded for your good deed with a larger refund next time around!

If you would like to discuss increasing your donation, or donating your tax refund back to us, please call Dianne Armstrong on **0800 663 463**.



Yes, I want to support New Zealanders affected by arthritis!

My details:

First name:

Last name:

Mailing address:

Please fill in this donation slip and post back to us:

Freepost 157311
Arthritis New Zealand
PO Box 10020
Wellington 6143

Enclosed is my donation of:

\$120 \$80 \$50 \$25 other:

I am paying by:

Visa Mastercard Amex Diners

Cheque enclosed (please make out to 'Arthritis New Zealand')

Card number:

Expiry date: / /

Card holder:

Signature:

Did you know that you can also donate online?

Visit www.arthritis.org.nz.

Thank you for your generosity!

Contact Us

Call free 0800 663 463

Call this number and ask to speak with one of our trained Arthritis Educators who will talk with you about managing your arthritis. They can advise you on medications, exercise, joint protection, pain management and healthy food as well as refer you to other community support or exercise groups.

Make a donation

Phone 0900 333 20 to make an automatic \$20 donation to support the more than 624,000 New Zealanders living with arthritis.

Visit www.arthritis.org.nz

Visit our website for information about the different types of arthritis, latest news, blogs, downloadable brochures, and more.

Offices

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Phone 03 366 8383

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