



Press Release

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Brain Tumour Support NZ

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Brain Tumour Patients to get support from Nelson Based Charity

Brain Tumour Support NZ, a Nelson based nationwide charity is launching a pioneering initiative to support Kiwis across the length and breadth of Aotearoa New Zealand.

Every year the lives of over 1000 New Zealanders are devastated with a diagnosis of a brain tumour which changes their life and the lives of their families and whānau forever. Brain tumours can affect anyone – male or female, young or old - any age, any ethnicity, and brain cancer is the leading cause of cancer death in children aged 19 and under.

Brain Tumour Support NZ aims to provide information, support and guidance to patients, their families and friends across all of Aotearoa New Zealand. They advocate for the best treatments, care and support for patients, so they can have the best possible outcomes and

quality of life. In addition to a dedicated website, online and phone support BTSNZ are launching their 'Brain Boxes'. Mandy says "We appreciate how difficult things can be once someone has been diagnosed with a brain tumour; the '4.00am moments', the travelling to and from appointments, the stream of questions that pop into your head, trying to remember the jobs of all the people that you'll meet on your journey, and knowing who to turn to and when. You just don't need that when you just trying to focus your energy on feeling better." So to assist brain tumour patients, BTSNZ has launched a unique and invaluable aid to keep on top of things.

The 'brain box' contains a number of essential things to support and provide information for brain tumour patients and their carers including six Patient Guides to help patients navigate their journey, information about the support offered and a whole bunch of good things to let people know that they are not on their own - right down to a box of tea and a packet of biscuits to have whilst digesting all this new information.

Receiving the news that you or a loved one has been diagnosed with a brain tumour can be a confusing and daunting time. Mandy Bathan knows this because In September 2017 she was living a busy life teaching new entrant children with three grown up children. She had a regular life most would recognise involving paying bills, juggling schedules and being with her grandson. Give or take a few road bumps, life was a place of children's laughter as well as dealing with the usual minutiae of life. Then abruptly and without warning things changed. She was diagnosed with an oligodendroglioma brain tumour and underwent the difficult journey of a six- hour brain surgery operation followed by the long process of getting back to some sort of normality. It was at this time she realised that although websites carried lots of information it seemed contradictory and overwhelmingly complicated. She realised that there had to be a better way to help brain tumour patients and their families in New Zealand and decided she was going was to set up a charity to help others navigate the warren of obfuscated information and blind alleys of brain tumour information on the web.

From her home in Nelson Mandy realised there was no single source of information for Kiwis to access. The threads of data and information from websites across Canada, UK, USA and Australia bore little relevance for people living on the remote West Coast nor indeed

the sprawl of Auckland where people could find themselves working through a geographically distanced opaque health system. There had to be a way to help vulnerable patients and families here in New Zealand.

Using the whakatauki, *He waka eke noa* (we are all in this together) and fortified with nothing more than her phone and laptop, Mandy decided to start the charity so that if someone hears the words 'you have a brain tumour' BTSNZ will be there to provide the support.

Notes to editor

ABOUT BRAIN TUMOUR SUPPORT NZ

Brain Tumour Support NZ is a registered charity formed in 2019 to provide much needed support, information and advocacy to brain tumour patients in New Zealand. Their office is in 189 Bridge Street, Nelson. Their Vision is that everyone living with a brain tumour has the support, information and access to best treatments, so they feel less afraid, less alone and more empowered. Website: www.braintumoursupport.org.nz

SUPPORTERS

English illustrator Quentin Blake, CBE supports the charity and was major initial donor to help start the charity.

Other supporters include Erena Mikeare, Bay of Plenty Magic netball player and Tony Cribb, New Zealand 'Tin Man' artist

BTSNZ has also received a grant from the Rātā Foundation

INTERNATIONAL BRAIN TUMOUR ALLIANCE

Chris Tse is a Senior Advisor for the IBTA and in 2019 Chris and Mandy attended the International Brain Tumour Alliance conference in Washington DC which helped create sustainable relationships with other organisations from as far afield as Japan, Belgium and Singapore.