

The newsletter of the Charcot-Marie-Tooth Association of Australia Incorporated, providing information and support for people with Charcot-Marie-Tooth disease and their carers, health professionals and friends.
VOLUME 91 Autumn 2019



CMTAA
Charcot-Marie-Tooth Association Australia Inc.

The CMT CoMmuniTy

LEAVING A BEQUEST IN YOUR WILL

A Story of Hope and Giving

Denis Northwood was born in Goulburn NSW in 1946. He spent most of his childhood in Sydney. He was one of six siblings and this article has been prepared following consultation with them. Their earliest memory of Denis's malady was that he loved to walk barefoot everywhere, even on hot tarred roads in summer.

He was prone to having accidents. One example - as a young teenager he jumped off the chook shed roof onto an upturned rake and it went through his foot. Mum called the ambulance as she didn't have a car to take him to hospital. The hospital doctor told Denis he was very brave as his foot was being stitched. Denis became a wool classer and worked in Australian and New Zealand wool sheds. He also drove heavy machinery for mining companies in remote locations such as Innamincka and Thargomindah. Later he worked for the PMG (pre-Telstra) digging trenches and laying cables by bulldozer, which he said, jangled his entire body for days afterwards. He bought a property at Mullumbimby and for 30 years he maintained it like a park. Growing his own food (meat, fruit and vegetables) was a priority. Denis was a keen photographer and golfer. He loved country music. Denis took up square dancing and later began a local square-dancing club, often calling the dances.

Denis first became aware of CMT when a friend visiting Sydney saw a TV interview with Dr Garth Nicholson. Then Denis's grandchildren were seen toe-drop walking at a family wedding and the genetic history of CMT became evident.

Denis's entire family and his five siblings were tested at Concord Hospital by Professor Garth Nicholson on 19 January 2001. Denis's family were found to have mild forms of CMT (we think Denis had 1A). He had problems with manual dexterity and hand strength, so he had shatter-proof melamine dinner-ware, all taps had lever-handles and none of his clothes had buttons. In later years, Denis had surgery on both hands (to improve his grip) and both feet. But he continued to be able to work on his property and enjoyed walking on Byron's beaches and swimming. He received excellent medical support from a range of medical practitioners in the area. Denis died at home in 2018, from lung cancer, just short of his 72nd birthday.

Maira Castle (Denis' sister)



CMT Australia would like to acknowledge the generous donation given by Denis towards research into CMT.

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Our greatest glory is not in never falling but getting up every time we do—Confucius

PRESIDENTS REPORT



Welcome to Autumn 2019.

I hope that the year, thus far, has been kind to you all.

What a busy start to the year the CMTAA has had, with the CMNTAA Aussie Kids camp already over for the year, a wonderful site tour of the research facilities at

Concord Hospital hosted by Professor Marina Kennerson, the Aussie Kids out and about sailing on Sydney Harbour, and a wonderful fund raising performance by UK Horn player, and fellow CMter, Chris Griffiths at St Jude's in Bowral.

Your new committee is working well, and I am really pleased with how Lisa and Chris have jumped, boots and all, into many of the activities we are looking at implementing from our Strategic Plan.

I am also very pleased that our Victorian committee have taken up the challenge of hosting our Annual Seminar in Melbourne this year. It is great to be able to share these around the country with Tasmania delivering a magnificent seminar last year, and Sydney lined up for 2020.

I have penned an article for this newsletter on the issue of travelling with CMT, in particular the issue of travel insurance. If any members have had a particular story of their CMTY travel insurance experiences, please let us know. If we have sufficient feedback we may publish a follow-up article in a forthcoming newsletter or on our Facebook site.

Hope you all keep well over the upcoming winter.

Be kind to yourselves

Tony

NEWS FROM THE REGIONS AND STATES

TASMANIA

We had a good attendance at our Get-together on Sunday 3rd March with 18 folk sharing stories and eating a sumptuous afternoon tea! We had a demonstration from one of our members who talked about her journey to find comfortable orthotics which started discussion. We all swapped names of podiatrists, physios etc. This is why it is so important for CMT folk to be part of a Support Group as they can talk to like minded folk and gain valuable information. This was the first opportunity for us to get together following the Seminar last year with comments about just how much they benefited by the Seminar.



I had my six monthly visit to my neurologist in January and we talked about the Seminar. When I asked him if there had been any feedback - he held his head in his hands and said that he has been swamped with folk being diagnosed with CMT! So the word has got around! Another comment from a doctor that I saw in an emergency department – “CMT? You don’t hear much about it these days” Well - hello – you are about to hear a lot more!!

The photo shows some of our Support Group enjoying afternoon tea. “

Marilyn Kremmer

Tasmanian Coordinator CMT Australia



GOLD COAST

Hi all, I hope that you are feeling good and that things are going well for you and that the heat and humidity are not affecting you to much. A wonderful compliment was paid at our Coffee and Chat morning, when one of the members stated that they enjoyed coming to these mornings as it is so relaxed and friendly, and isn’t that what it is all about? So if have been thinking about joining one of the mornings in your area, please do, as I am sure will enjoy the experience. As I have had a few health issues of late, not much has been going on, but I am going to hold a catch up about the middle of April, more on that later. So take care, keep smiling and may God bless, Judy.

NEWS FROM THE REGIONS AND STATES

MELBOURNE

Hi Victorians,

I hope everyone had a lovely Christmas and was out and about enjoying the summer season.



Your CMTVIC committee met in February and March to plan the National CMT Awareness Day Seminar to be held in Melbourne on the 21st September 2019, please refer to the section in this newsletter dedicated to the Seminar for more detail.

We also have the following events planned and it would be lovely to see many more members at a few events, so come and join us and get to know your fellow CMT warriors.

Upcoming Events:

Saturday 4th May, 10.30am Coffee catch-up at the Convent Bakery in the Abbotsford Convent, 1 St Heliers Street, Abbotsford.

Saturday 3rd August, 10.30am Coffee catch-up at the Convent Bakery in the Abbotsford Convent, 1 St Heliers Street, Abbotsford.

Saturday 21st September, 10am – 4.15pm National CMT Awareness Day Seminar at Muscular Dystrophy Australia, 111 Boundary Road, North Melbourne

Saturday 5th October, 10.30am Coffee catch-up at the Convent Bakery in the Abbotsford Convent, 1 St Heliers Street, Abbotsford.

Sunday 1st December, 11am Christmas Family Day, venue yet to be confirmed

We would love to see more coffee catch-ups happening around the state but we are relying on you the members to volunteer to host a catch-up in your local area. Abbotsford is central for the inner Melbourne suburban areas but if you find that difficult to get to then let us know where you are located and if you can pick a cafe for members to meet up for a coffee we can then let everyone know of the venue and the time. Feel free to contact me via email paula_denise@bigpond.com, i will look forward to hearing from you.

As well as email notification, members can also refer to the CMTAA Victoria Support Group on Facebook, this is a closed group so please join and keep up to date with information and updates on activities.

Warm Regards, Paula Hodgson

NEWS FROM THE REGIONS AND STATES

NATIONAL CMT AUSTRALIA SEMINAR HEADED FOR MELBOURNE

National CMT Awareness Day Seminar, Melbourne 21st September 2019

We are pleased to advise that the National Seminar will be held in Melbourne on the 21st September, 2019 at Muscular Dystrophy Australia, 111 Boundary Road, North Melbourne.

Speakers on the day will include Prof Garth Nicholson, Prof Joshua Burns, the CMT Aussie Kids and we are working on locking in speakers to cover NDIS, Genetics, Exercise, Orthotics and a motivational speaker.

For those travelling to Melbourne and looking for accommodation you may like to consider the following two hotels that are a short tram or taxi ride to Muscular Dystrophy Australia:

Mercure North Melbourne, Cnr Flemington Rd & Harker St, North Melbourne +61 (0) 3 9329 1788
Email: reservations@mercurenorthmelbourne.com.au www.mercurenorthmelbourne.com.au

OR

Ibis Melbourne Hotel, 15-21 Therry Street, Melbourne Phone (03) 96660000.

www.hotelsone.com/melbourne-hotels-au/ibis-melbourne-hotel-and-apartments.html

Looking forward to seeing you at the seminar

Warm Regards,

CMTVIC Committee

CANBERRA AND A.C.T.

Our Canberra meeting in February was nearly over before it began! Despite the room booking having been checked and re-checked, when we arrived on the night the door was firmly locked, with no chance of raising someone after-hours to unlock it. However, we all know that people with CMT have to be resourceful when things don't work properly.

An advertising screen in the foyer was hacked to provide a display for PowerPoint slides, furniture was hijacked from the nearby cafeteria and set up in the middle of the hallway and life-saving equipment was borrowed from the first-aid room so that refreshments could be provided for supper. Residents entering the building were bemused, but not alarmed, to find a meeting set up right in the middle of the main thoroughfare!

Fortunately, the guest speaker for the night was our own Robert Twin, CMTAA treasurer, who spoke about some of the detailed goals of the CMTAA Strategic Plan. It was excellent to hear of the work being done by the committee to achieve those goals and there was plenty of discussion on how we members can assist in our own area. Overall, it was a very successful meeting, despite the initial setbacks.

Gabrielle Evans

NEWCASTLE

Hi all, I hope you all had a happy Christmas and New Year. Our first meeting for the year will be held on Saturday the 4th May, 2019. If anyone is interested in attending one of our meetings please don't hesitate to call. It will be good to see some new faces. Having CMT can make life difficult and it's good to meet regularly and socialise with others who have the same problem. I find we can always learn something new from others even though CMT can be very individual. I haven't been to a Seminar for a long time so I'm hoping to go this year and catch up with our CMT family at Concord. They do a tremendous job running the office and organising Seminars each year for our benefit.

That's all for now, take care and don't let CMT get you down.

Gabby Cosgrove - Newcastle CMT Co-ordinator

AOINC

Asian Oceanic Inherited Neuropathy Consortium

The Asian Oceanic region represents a large portion of the world population and in 2016 the Asian Oceanic Inherited Neuropathy Consortium (AOINC) was established. Charcot-Marie-Tooth (CMT) disease is the most common form of inherited neuropathies. The AOINC's belief is that bringing together a network of clinicians and scientists will enable collaboration to achieve greater insights into the causes and natural history of inherited neuropathies in the region thereby leading to the discovery of effective therapies and improving patient care. Members include Assoc Prof Marina Kennerson from the Anzac Institute at Concord Hospital and Prof Joshua Burns from the Children's Hospital at Westmead.

Assoc Prof Kennerson is the nominated AOINC Scientific Secretariat and has been working to build ties with the North American/European Inherited Neuropathy Consortium (INC) and also invite additional countries from the Asian Oceanic region to join AOINC. In 2018 she launched the AOINC website (www.asianoceanicinc.org) which shows the involvement of Australia, China, India, Japan, Korea, Malaysia, New Zealand, Singapore, Taiwan and Thailand.

The AOINC will help sustain a network of researchers and clinicians working on inherited neuropathies that will:

- contribute to the worldwide effort to diagnose and treat children and adults with inherited neuropathy
- expand knowledge by promoting communication and collaboration to achieve shared common goals for the inherited neuropathies
- support training and education of members to facilitate research excellence

It will also aim to establish country based Patient Registries to facilitate sharing of clinical information within the region and worldwide for clinical trial readiness and finally initiate public education and develop patient advocacy groups in the region to increase awareness of inherited neuropathies in the Asian Oceanic region. CMT Australia is excited to see this new initiative in the world of CMT and plan to attend the 2019 Meeting to be held in Sydney.

NEW FACT SHEET

The Centre for Genetics Education as part of the NSW Government Health Department have a new fact sheet on Reproductive Carrier Screening. This screening is a blood or saliva test that looks at a person's genes, which contain the instructions for growth and development.

This fact sheet can be accessed by going to:

<https://www.genetics.edu.au/publications-and-resources/facts-sheets/FS65REPRODUCTIVECARRIERSCREENING.pdf/view?searchterm=reproductive+carrier>

CMT Australia Goes Sinfonic

CMT Australia spent a wonderful morning in March at Bowral on the Southern Highlands of NSW. Chris Griffiths, who has CMT was invited to perform in the Highlands Sinfonia Concert with his specially adapted horn. Chris performed the Horn Concerto No. 1, Opus 11, by Richard Strauss in the beautiful historic St Jude's Church at Bowral. Chris is an accomplished musician but was having difficulty reaching the various levers necessary to



play the different notes due to the restrictions CMT placed on his hand movements. So he had his horn adapted to swap the location of the levers. As a result of his CMT Chris is also a double amputee. Chris' sister, Heather Powrie also performed with the Sinfonia playing the viola.

Thank you to our CMT Australia supporters for attending on the day and the Highlands Sinfonia for their contribution. All profits from the concert will go to CMT Australia, making a difference to our CMT family across Australia.



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CMT AUSSIE KIDS GET ACTIVE



CMT AUSSIE KIDS WEEKEND 2019

#cmtaussiekids 22 kids enjoyed a fun and adventurous weekend at the Berry Sport and Recreation Centre on the south coast of NSW early in March. The camp has been running since 2012, and has positively impacted over 50 families throughout that time. Now in its 8th year, the Camp is aimed at kids living with Charcot Marie Tooth aged 8- 10 years and over. It gives these kids a chance to mix with others of the same age who have CMT and who understand what it's like to face the challenges CMT brings every day. During the camp, the kids have the opportunity to participate in both active and passive activities, and, most importantly, understand that they are not alone in living with CMT. Past participants have formed strong friendships and regularly stay in touch through social activities and social media.

Our recently established Mentor Program saw 5 young adults with CMT lead the group in many of the activities over the weekend. These Mentors have been with the camps since the early times and bring an empathy, understanding and enthusiasm to the group. Peter and Jillian Critchley were still at camp, fully involved in all activities, steering the ship. However we must congratulate Eliza, Ewin, Josh, Matilda and Steph on their leadership over the weekend and look forward to the future.

We enjoyed such activities as Raft Building, both a physical activity and a team building exercise; pool games, Archery and a Giant Swing built overlooking the campsite. Saturday lunch was freshly prepared pizzas, cooked in the outdoor pizza oven...in the drizzling rain...but we didn't care. We just smiled and got on with it!

Gabe Donlevy, from the Children's Hospital at Westmead visited during the Saturday afternoon to help bridge the gap between the kids and hospital. The relationship between CMTAK and the CHW is well established and is a wonderful opportunity to develop understanding on both sides.

The feedback survey conducted after camp tells us that over 90% of this year's attendees will be back absolutely for the 2020 camp. Email cmtaussiekids@gmail.com to receive updates on all Youth activities.

SAILORS WITH DISABILITIES

#SWD How about this for a fun day for the CMT Aussie Kids! Take one 54ft sailing boat, add Sydney Harbour and 15 CMT Aussie Kids and their families and Wow! Sailing with Australian-based charity Sailors with Disabilities, we left the CYC Marina in Rushcutter's Bay heading up beautiful Sydney Harbour towards the Heads before turning west down past the Sydney Opera House, under the



Sydney Harbour Bridge and as far as Balmain before returning to Rushcutters Bay. During the sail, the CMT Aussie Kids had the opportunity to help out; helping with the sails and even steering the boat. Our skipper David Leslie was a proud example of keeping fit with CMT. He introduced himself to the kids as 'Hi, my name's David and I'm the skipper of this boat...and I have CMT!'. Thanks to David and all the volunteers at Sailors with Disabilities for a great day out.

LABORATORY VISIT

#labvisit #anzacinstitute Nearly 20 CMT Aussie Kids families and friends gathered for a fascinating insight into the research going on behind the scenes into CMT. Guided by Assoc Professor Marina Kennerson, and her team at the ANZAC Institute at Concord Hospital the group took a tour of the lab, extracting DNA from strawberries, and watching microscopic worms being used for research into CMT cells. They also used electron micro-



scopes to view mitochondria grown from skin cells. We finished off the day with a BBQ lunch and informal chat with the researchers. It was a compelling vision into how these scientists are working towards finding treatments and a cure for CMT. Thanks go to Marina and her team for their wonderful welcome, but more importantly, their wonderful work.



TRIPS FOR TRAVEL INSURANCE

Let me share a story with you. A few years ago, I was travelling in Rome with my wife. We were staying in a lovely apartment near the Colosseum. As we were staying for a week I bought a six pack of 1.5 litre water bottles to carry back to the apartment (about 750 metres). In carrying it, I did my lower back a significant damage, creating significant pain and requiring daily medical treatment. We needed to extend our time in Rome as I was unable to travel. I claimed these medical expenses on my travel insurance. The insurance company got in touch with my GP, asking for a full medical background and questioning my GP about any instances of back injury in the past (there were none).

They were clearly looking for an excuse to not pay based on me failing to declare a pre-existing medical condition. I had declared my CMT. Naturally they paid my expenses. But the LESSON IS CLEAR - if you travel with CMT and fail to declare it the insurance companies will either (1) try to link any injury to your CMT and thus not pay or (2) argue that you breached your contract by failing to tell them about everything that may impact their risk.

The clear lesson is that I would strongly advise that you always disclose your CMT in your travel insurance. Legally, it does not matter whether you have been "tested" or not. If you know something that may impact the risk faced by the insurance company you are legally obliged to declare it.

Fortunately, many insurance companies now use "on-line" risk assessment tools that usually know about CMT, ask a few extra questions and either accept for no charge or, depending on severity, might increase the charge a little. Below is an example of one of these automated question tools. -

Initial Question - I clicked YES

Travelling with medical conditions

Every year, we help many Australians travel with a wide range of medical conditions. If you or any of your travelling companions have a pre-existing medical condition, we will ask for some further information so we can confirm your cover.

For more information about what we consider pre-existing medical conditions to be, please click [here](#).

[What happens if I don't declare a pre-existing medical condition?](#)



Do any traveller(s) have pre-existing medical condition(s)?

No

Yes

Next Question - asks what I have - as I start typing Charcot - it offers a list and I choose Charcot Marie Tooth.

What we automatically cover → What we don't cover → Medical details

Please enter your medical condition here:

charl

Search

Please select a medical condition

Charcot foot

Select

Charcot joint

Select

Charcot Marie Tooth

Select

Charge syndrome

Select

Mucopolysaccharidoses

Select

Charcot Marie Tooth

Press Finish if you would like to exit

Finish

With TONY ADAMS, CMT AUSTRALIA PRESIDENT

Asks a few follow up questions:

What we automatically cover → What we don't cover → Medical details

Charcot Marie Tooth

Do you currently use any mobility aids?

☐ Walking stick or frame

☐ A wheelchair or mobility scooter

☐ Wheelchair or mobility scooter AND walking stick or frame

☐ I am confined to bed

☐ I don't use any mobility aids (able to walk independently)

☐ I use mobility aids because of an unrelated medical condition

For me - I don't use any of these aids so I click "I don't use and mobility aids (able to walk independently)"

Thank you for completing your medical assessment. Your policy now includes the following assessed condition(s):

Charcot Marie Tooth

You have cover for these pre-existing condition(s) with no additional premium payable.

Then I get: (very happy)

Policy summary

Policy: Comprehensive
\$434.52

I'm going to
Worldwide [VIEW MAP](#)

Travel dates
Departure 01/04/2019
Return 01/05/2019

Traveller(s)
Mr Joe Smoth, Age: 54

[Change Quote](#)
[Product Disclosure Statement](#)

Your details
All fields are required unless otherwise marked

Pre-existing medical assessment | Outcome

Traveller name	Mr Joe Smoth
Assessment Status	Approved: Declared pre-existing conditions approved, subject to payment of additional premium
Assessment Number	MA-WPAC-01686186-01

Approved: Declared pre-existing conditions approved, subject to payment of additional premium

Thank you for completing your medical assessment. For an additional premium your policy can include cover for the following assessed condition(s):

Charcot Marie Tooth

Would you like to pay an additional premium for cover of your pre-existing medical condition(s)? ☒ Yes ☐ No

Select your PE Medical Excess

Additional premium: \$120.23

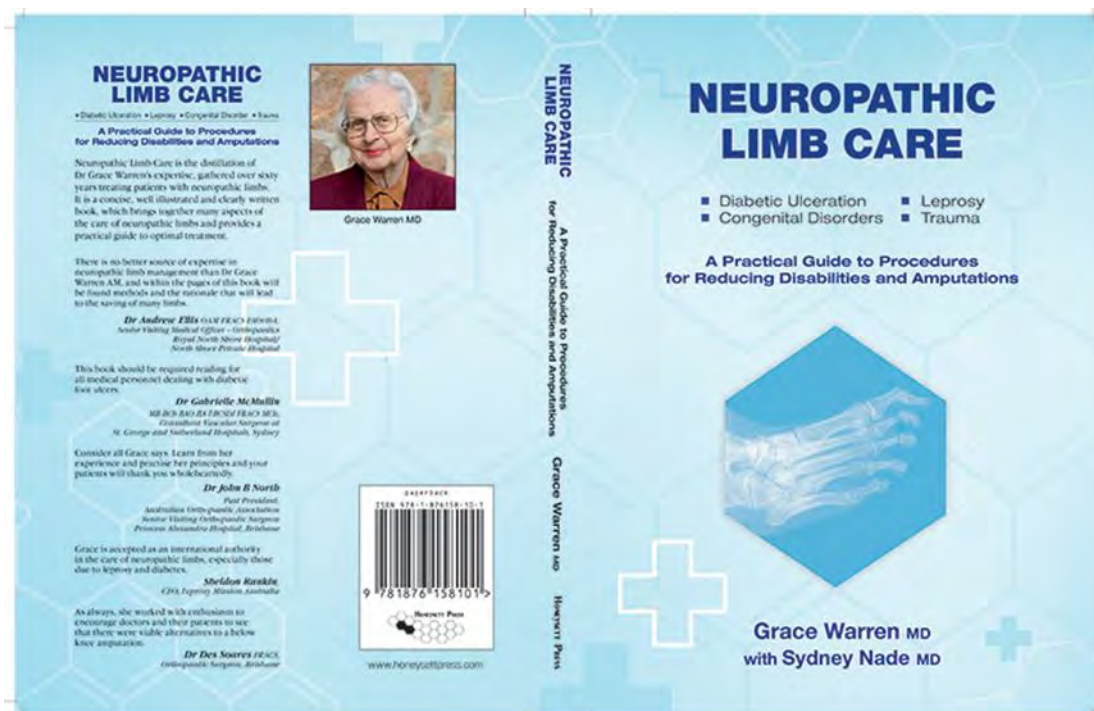
[Next](#)

If you do click some of the other options you may get a further question asking if you want the cover to include your CMT and then how much excess you want. In the example below. I have made up a passenger, aged 54, travelling worldwide (the most expensive premium) for a month. With an excess of \$200 the premium increases by \$120. This can be reduced by increasing the excess.

Many people with CMT travel extensively well into their old age with no problems. However, we are all susceptible to falls and thus also breaks, dislocations or other injuries. You don't want to be stuck overseas without travel insurance because you failed your legally contracted obligation to disclose your CMT. It is now easy to declare your CMT and I would urge you to ensure you find an insurer that uses an assessment form like this when you buy your insurance. Travel often and travel safe.

NEW PUBLICATIONS

Neuropathic Limb Care is the distillation of Dr Grace Warren's expertise, gathered over sixty years treating patients with neuropathic limbs. It is a concise, well-illustrated and clearly written book, which brings together many aspect of the care of neuropathic limbs and provides a practical guide to optimal treatment of patients with multiple neurological problems from many causes.



It is the purpose of this book to bring together many aspects of the care of the neuropathic limb to provide a practical guide to what can be done. In this way, medical workers at all levels can become aware of the possibilities of treatment, to whom they should refer patients, and who can advise about the special problems of neuropathy. This book has slowly grown out of many requests for teaching, for handouts, for articles, for lectures, and for practical demonstrations in many countries. In the last decade, there has been much more acceptance of the fact that the procedures that have become routine to us in the leprosy world have a place in the management of diabetes, spina bifida and familial neuropathy – to mention but a few of the commonest forms of long-term neuropathy.

Most of the principles in this book are those that are basic to good medicine and applied in a simple manner. A lot of complicated and expensive equipment is not needed in order to improve the quality of life of most patients with neuropathy. But the patient and the staff concerned must have a devotion to the job, tenacity, and the ability to adapt the principles given here to the immediate needs of patients.

This book is written to be easily understood and of use to all who are involved in the care of those with neuropathy. In my early days of practice, it would have been very useful to have a manual giving an overview of what can be done. We had to hunt for articles anywhere they could be located. Here the essentials are collected together. On topics like shoe-making, only the basic principles are covered; more space is dedicated to the less well-known aspects of care. Hopefully some patients will themselves find this book informative and helpful, in both developed and developing countries. The needs are very similar, and the methods of management are basically the same.

Available from Honeysett Press in digital or paperback format.

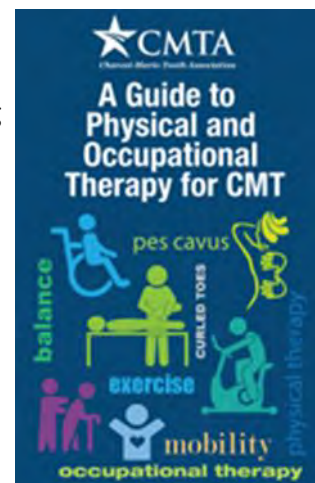
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Darryl Beitsch

NEW CMT PHYSIOTHERAPY AND OCCUPATIONAL THERAPY GUIDELINE

The CMT Assoc of America (CMTA) has recently launched a new and exciting document. Under the leadership of world-class CMT clinicians, including our very own Prof. Joshua Burns from the Children's Hospital at Westmead, the CMTA sponsored a workshop and brought together physical and occupational therapists from the Centres of Excellence to collaborate on a guide to help people with CMT and their therapists better understand and manage their CMT. They have created this comprehensive guide.

This first-of-its-kind publication outlines the assessment and care of people with CMT. As CMT manifests so differently from person to person, this guide, based on research, experience and patient input, will optimize collaboration between physical and/or occupational therapists and patients, helping ensure each individual gets the best possible care for their specific needs.



This invaluable document will empower people with CMT and their health care professionals to safely make educated decisions regarding a rehabilitative plan of action to maintain function and quality of life.

You can download it for free at

<https://www.cmtausa.org/news/a-guide-to-physical-and-occupational-therapy-for-cmt/>

IF YOU WOULD LIKE A HARD COPY OF THIS BOOKLET PLEASE CONTACT OUR NATIONAL OFFICE ON 02 9767 5015 OR EMAIL cmtaa2@cmt.org.au

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TASMANIA

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The **CMT CoMmuniTy newsletter** is produced approximately every four months for the information of CMT AUSTRALIA members. The Editor is Jillian Critchley.

All contributions, letters, and enquiries should be directed to the Editor, CMT CoMmuniTy newsletter, 15 Naranga Avenue, Engadine 2233 N.S.W. or email: cmtaa2@cmt.org.au

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ARTICLES AND IDEAS

Your letters and articles are very welcome. This is your newsletter. Let me know what you want. Ideas, letters, articles, photos, anecdotes...anything is welcome that is CMT related.

Deadline for next newsletter: 15th July 2019

Jillian Critchley

The Editor, The CMTAA CoMmuniTy

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