

REGISTERED OFFICE CONTACT: Secretary: Barbara M
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GENERAL ENQUIRIES: Chairman: Phil R
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EMAIL: phil.r@pnsg.org.au
Web: www.pnsg.org.au

Other Team Members:

Treasurer: Faye H
 Newsletter Distribution: Ninetta G
 Meeting Activity Coordinator: Celia M

BANK DETAILS: For submitting annual subscriptions, donations etc.
 Bendigo Bank: BSB No.633 000 - Acct No.125 154 856

Please: When making a payment we need to know your name and what the payment covers e.g. annual subscription, donation etc. Without this information we are unable to match the payment with your account.

NEWSLETTER /P.N. MINUTES: 10th March 2025.

The meeting opened at 10:03 am and Phil welcomed us all including a new member, Elizabeth.

CONFIRMATION OF MINUTES OF LAST COMMITTEE MEETING, as circulated as being true and correct.

Accepted: Faye H Seconded: Celia M

ATTENDANCE: Eileen S, Barbara M, Faye H, Phil R, Lindsay G, Mike K, Celia M, Ron and Beryl H, Faye B, Murray C, Ron G and Elizabeth.

APOLOGIES: Suzanne and Dan D, Aussie and Wendy N, and Laural M.

CORRESPONDENCE (INC. EMAILS):

1. CONNECT GROUPS – PEAK POST – Newsletter.
2. Sadly, one of our members, Grace Cade, passed away. Condolences to Richard.
3. Email from an existing member Eileen S. re: fees etc.

4. Email from Ninetta advising us that she has been very unwell. She would like a Sunflower lanyard when they're available. We thank her for doing such a fabulous job doing our newsletter every month. We wish her all the best and hope she feels better soon.
5. Thanks to Curtin Radio and The Senior Newspaper, we've received six requests for info about what we do and what we have to offer.

Accepted: Phil R

Seconded: Faye H

TREASURER'S REPORT (as of 1/03/2025)

RECEIPTS	\$	PAYMENTS	\$
Membership D.D.	20.00	1 x Web Site Hosting	9.23
Joining D.D.	0.00	Curtin Radio	88.00
Donation D. D.	0.00	Postage	27.28
Accident Cr. D.D.	0.00		
TOTAL	20.00		124.51
Balance b/f			7769.81
BANK			
Postage	27.28	Deposits	20.00
Curtin Radio.	88.00		
Webpage D.D.	9.23		
Balance c/f	7665.30		
TOTAL	7789.81		7789.81
Balance c/f			7665.30

ACCOUNTS FOR PAYMENT

Postage	0.00
1 Mth Website	9.23
Purchase-Accident Cream	235.40
TOTAL:	244.63

Approved: Lindsay G

Seconded: Eileen S

PLEASE: Remember to include your name and what your payment covers when paying online. Faye (our Treasurer) has many members all paying similar amounts online and without your name and what you're paying for then Faye has little chance of knowing from whom the payments came and what the payment is for.

GENERAL BUSINESS:

1. New Member(s):

Our new member, Elizabeth, was introduced and members were able to discuss with empathy, her P.N. symptoms and illness. Some members detailed their own struggles with PN and provided some solutions helping them live with PN and small nerve fibre damage. However, it is reiterated that each solution, be it creams, or even cannabis treatment etc. do not help everyone.

2. **Sunflower** – In regard to the “Sunflower” lanyards to aid people with hidden illnesses receive help to navigate their way in Westfield shopping centres and in particular, the airport, we have paid our membership, and a batch of Sunflower Lanyards have arrived and are available if they are needed. However, the member handling the distribution of the sunflowers is on ‘sick leave’ at the moment but will hopefully be back in April. He will sort things out when he returns.

3. The Senior Newspaper:

The article run by The Senior Newspaper is producing good results. Phil R said he’s receiving 1-2 calls a day from PN sufferers mostly from other states than WA.

<https://www.thesenior.com.au/story/8888661/struggling-with-pain-peters-battle-with-neuropathy/>

4. We have received several enquiries from PN sufferers thanks to Curtin Radio and The Senior Newspaper. The gentleman, Peter, about whom the article was written in The Senior, has shown a strong interest in starting up a group in South Australia under the PNSG banner. Phil has had brief discussions with Peter who is quite keen to proceed as the group leader.

By us setting up a group in SA will add some extra work for managers do. For example, Faye would need to set up provision in her chart of accounts that would accurately track income and expenses of the SA group. Peter’s main responsibility would be to identify and set up new members then run his own monthly meeting just like us.

Peter will be an extension of PNSG Perth and will need to follow our well tested internal systems and practices. Peter has said he’s happy to do this and he and Phil R are developing a written plan and agreement to minimise misinterpretation.

We’ll still have only one newsletter and that would include both WA, and SA. The newsletter would still be managed and controlled by us.

5. Continual Improvement:

- a. PNSG Website - Phil R brought up that we, as a group, need to keep improving our website. There is a basic form on our website to collect ideas to improve with any comments on problems encountered, improve on the website, and forward any suggestions which may help us.
- b. Radio Advertising – Lindsay G suggested that Phil R contacts Curtin Radio (to which we subscribe) to determine the names of similar radio stations to Curtin in other states of Australia. Phil R noted the suggestion and will report back.

There were no further subjects to discuss, and the meeting closed at 10:43 am.

Our Next Meeting:

The next monthly meeting will be held on Monday 14th April 2025 at The Niche, Cnr Aberdare Road and Hospital Avenue, Nedlands from 10.00 am to 12 noon.

My PN Journey Thus Far

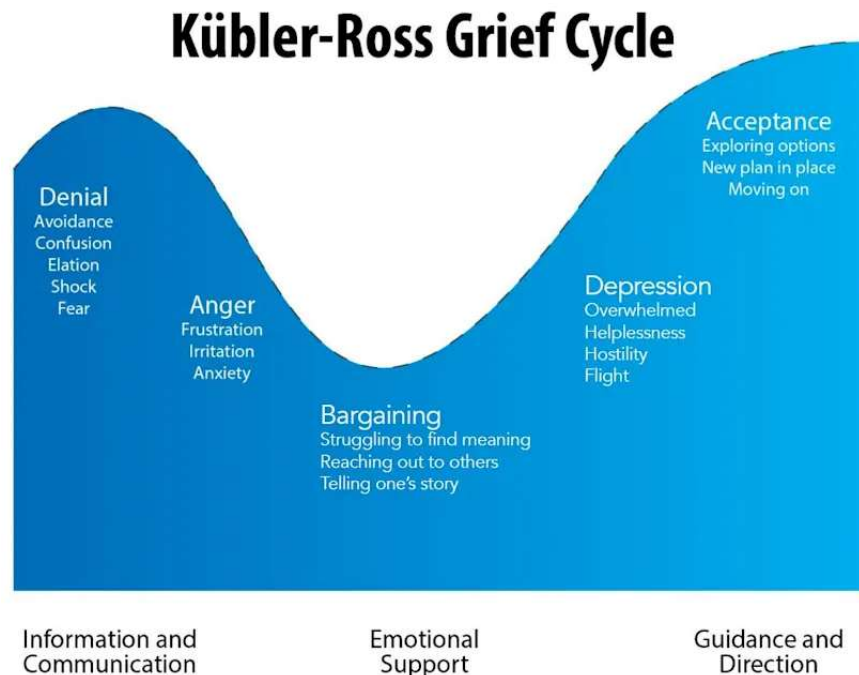
I thought I would share my journey with you in the hope you, the reader will gain something from it. It's important to say I mention several products that I've purchased, and you can do too however I do not receive a commission or any other kickback from manufacturers and/or suppliers.



For more than seven years now I've had small fibre PN (the painful sort not the sensory balance sort).

I've spent a small fortune (and I'm continuing to do so) on every treatment I stumble across e.g., creams, lotions and potions and every conceivable gadget.

I seem to be following the Grief Model well.



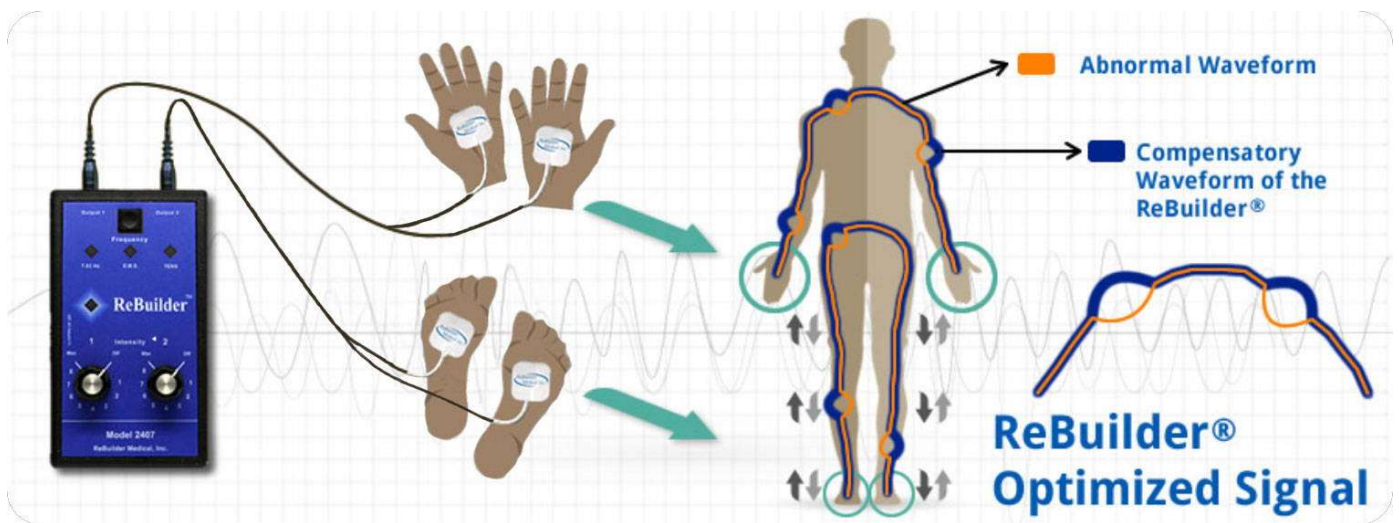
It's taken me seven years to go from "Denial to Acceptance" but I'm very glad I'm where I am as opposed to where I used to be.

I wouldn't be where I am if it weren't for number one - medications (which of course only treat the symptoms not the cause) and number two distractions (anything that's legal and moral that takes your mind off the pain).

Talking of distractions... I love gadgets.

I've tried /trying (not in any sequence):

1. Electrotherapy involves an electrical pulsing device powered by a 9v battery. To use it properly, both feet must be placed in a bucket of water. The Rebuilder manufacturer claims that its product is more than just a TENS (Transcutaneous Electrical Nerve Stimulation) or EMS (Electronic Muscle Stimulation) device, asserting that it can correct abnormal nerve waveform.



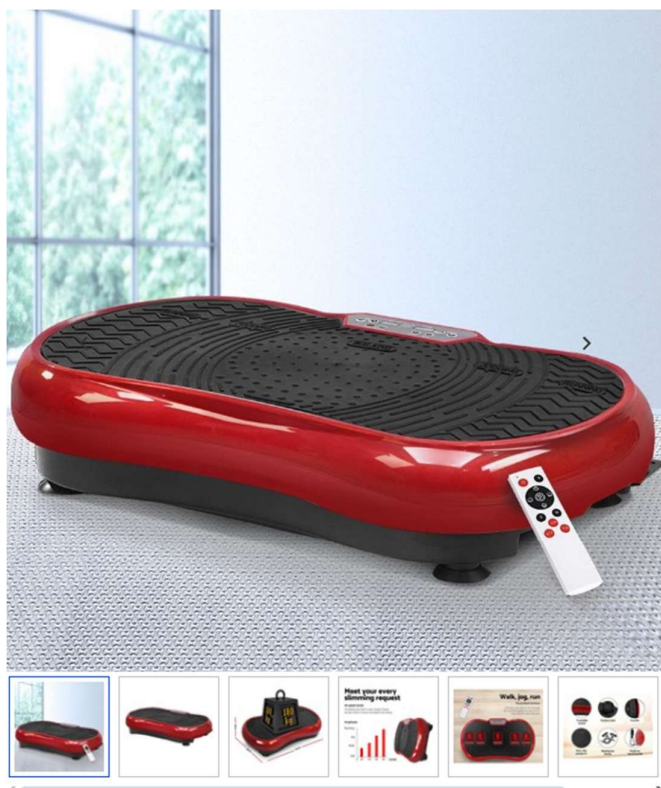
Click on this link to find out more: <https://rebuildermedical.com>

-ooOoo-

2. Everfit Mechanical Vibrating Platform – Available from many places including Big W:

https://www.bigw.com.au/product/everfit-vibration-machine-platform-resistance-rope-home-fitness-dark-red/p/9900144940?gclid=Cj0KCQjwTJ6_BhDWARIsAGanmKepzves1efWKWy6mbxgVw2n1bHXpCtHJsKfewYhYjhvgv3LM5SefLwaAhkAEALw_wcB

You can stand, sit, kneel, or lay while each end moves up and down. This activates your muscles to counteract the movement, thus toning them. Adjust the speed and intensity by positioning your feet closer together or further apart.



Everfit Vibration Machine Platform Resistance Rope Home Fitness Dark Red

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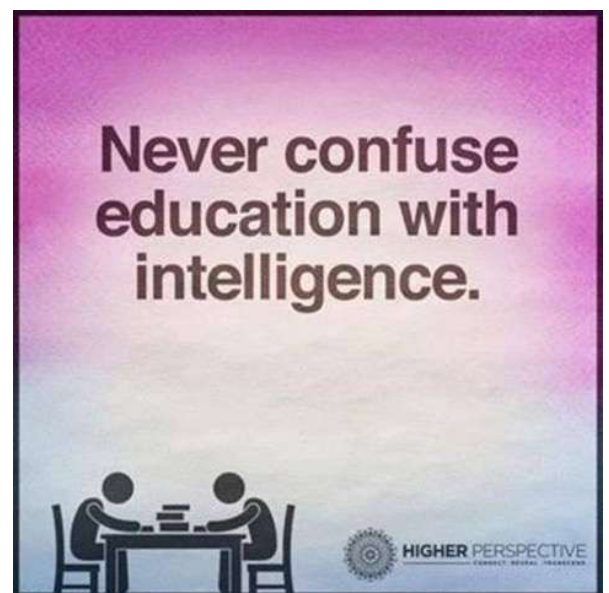
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"My Journey" continues next month where I explore options in the USA



Only in the USA?

My coffee cup reminding me why I shouldn't have a donut with it.



Thank You and Good Night!