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GENERAL ENQUIRIES: Chairman: Phil R

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**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

NEWSLETTER /P.N. MINUTES: 8<sup>th</sup> July 2024.

The meeting opened at 10:05 AM and Phil welcomed us all.

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

Accepted: Dan D Seconded: Celia M

ATTENDANCE: Barbara M, Laurel M, Celia M, Wendy N, Beryl H, Suzanne D, Margaret H, Mike K, Austin

N, Ron H, Dan D, Phil R and Ron G.

**APOLOGIES:** Eilene Grace C, Faye H, Lindsay G, Richard C, Murray C and Philip S.

### **CORRESPONDENCE (INC. EMAILS):**

**MAIL: CONNECT GROUPS** – Updates from the Peer Support Sector. Pay it forwards funding is now available for 2024/2025. It is aimed at peer support groups and projects that focus on improving mental health etc., amongst other areas.

Funding up to \$10,000 is available to Connect Group members who fit the guidelines.

Applications for review of applications close Tuesday 13th August 2024.

Last day to submit applications is Tuesday 27<sup>th</sup> August 2024

Accepted: Suzanne D Seconded: Margaret H

#### TREASURER'S REPORT

RECEIPTS	\$	PAYMENTS	\$
Attendance	34.00	Postage	98.89
Membership	0.00	Morning Tea	20.00
Donation	0.00	Honorariums	600.00
Membership D.D.	140.00	Membership (NCWA)	100.00
Joining D.D.	5.00	Stationery	32.48
Donation D. D.	60.00		
Accident Cr. D.D.	0.00		
TOTAL	239.00		851.37
Balance b/f			
BANK			
Cheque A/c paid	851.37	Deposits	239.00
Balance c/f	1473.94		2086.31
TOTAL	2325.31		2325.31
Balance c/f			1473.94
ACCOUNTS FOR PAYN	ΛΕΝΤ		
Postage	0.00		
Morning Tea	0.00		
Stationery	0.00		
TOTAL:	0.00		

Approved: Celia M Seconded: Mike K

### **GENERAL BUSINESS:**

A member queried why we had the logo of WA Lotteries Commission on our letterhead. Ron G. explained that we received a donation years ago from Lotteries Commission with the proviso that we have logos on any advertising material. As it was very hard to obtain donations from them at the time, we have concurred with their wishes.

#### Phil R. REPORTS

- a. Announced that he'd made a mistake in last month's newsletter. It was Dan D and not Ron G. who suggested his ideas on privacy and security.
- b. Reported that the joining fee was now \$20.00.
- c. Summarised for the month in saying that Faye H, Ninetta and Barbara M were in playing their part and keeping him up to date.
- d. He'd tried to contact ABC News Radio and Curtin Radio but was unable to get through, so he has left messages.

- e. Regarding membership applications, we are starting to get more interest from potential new members, including from the eastern states.
- f. We need to find a way to help our members contact us and give feedback on what they want to get from our support group as we're getting very little feedback on that score, even though we are trying to keep the information out there.
- g. We are trying to obtain a grant from ConnectGroups to finish off the website online setup.
- h. Our AGM is in 3 months' time, and we need to be able to identify in which direction you, the members, would like us to go if you have any other ideas to those being put forward.

**Developments in PN Research** – There's quite a lot going on around the world, mainly in the U.S.A., however it's all very exploratory and extremely detailed and technical for us to understand and explain. Online links can be shared; however, a computer, tablet or phone will be needed to read the information. If anyone is interested, can you let Phil R know and hard copies will be made available.

**Guest Speakers:** It takes a lot of time and energy to find guest speakers and even more to find ones that are memorable (in a good way). So, it's not something to be taken lightly.

Can you let Phil R know your preferred topic, keeping in mind a speaker can only deliver one main topic at a time as they will only have 45 minutes to an hour to speak and answer questions.

Some speakers require a minimum number of people to address and this may mean we join forces with other groups of similar needs for us to make the number up, which takes even more time to arrange.

Once we arrange a guest speaker, we need to do everything in our power to have members attend, or it will be an embarrassing disaster.

**Privacy and Security:** Privacy and Security is still very necessary to protect our assets and reputation. Please ASK if you think you are being scammed as there are several very clever people at PNSG who have experience in these matters.

### **General Discussions:**

- a. The variety of creams members use to relieve their aches and pains was discussed and, again, they didn't suit everyone. Restorate was effective for one member and another using Zostrix cream found it beneficial for his complaints. Some others used our Accident Cream and found it beneficial while other members weren't very impressed with it, although Phil R found Accident cream \*(available from PNSG) is an excellent moisturiser.
- b. A member brought in an EMS electrical foldable foot mat for general viewing. This is available on the internet for \$50.00. much more affordable than other versions.
  "Through EMS technology this product is available as a foot mat. The mat provides stimulation for feet, ankles, Achilles tendons as well as calf muscles for muscle contraction which primarily boost blood circulation. The EMS foot mat helps with electrical muscle stimulation by sending electrical pulses from the detachable control unit. Details and specifications regarding the foot mat can be checked out on the internet." Phil R said members can contact him should they require assistance.
- c. From the Westfield website: Westfield is a proud participant in the Hidden Disabilities Sunflower Scheme which helps to support and raise awareness of those living with a hidden disability in Australia and New Zealand.
  - Since being established in 2016 at Gatwick airport, it has been adopted by 170 airports across the globe. The Hidden Disabilities Sunflower Scheme is about helping people with disabilities which are not immediately obvious, such as autism, chronic pain, dementia, anxiety, visual or hearing impairment to attain the understanding, patience and assistance needed when going about their daily lives. Under the hidden Disabilities scheme, people with such disabilities can choose to wear a lanyard bearing a sunflower logo as a subtle way of letting the retailers know that they may require additional support, or assistance, or a bit more time when visiting the Centres.

The sunflower lanyards are now available in the Westfield centres at the Concierge desk across Australia and New Zealand.

In addition to making the Sunflower Lanyards available, Westfield Centres are training their staff and retailers to identify the Hidden Disabilities Sunflower so they can better support the customers who need additional help.

The sunflower emblem is also recognised at the Perth Airport. The Perth Airport team has been trained to recognise the lanyard and how to provide the best assistance and support customers may need, which doesn't mean jumping the line through customs etc. Lanyards are free at Perth Airport after filling in the correct form found online <a href="https://www.perthairport.com.au/at-the-airport/accessibility-at-perth-airport/hidden-disabilities">https://www.perthairport.com.au/at-the-airport/accessibility-at-perth-airport/hidden-disabilities</a>

A Distraction /Social Interaction Activity from Phil R – He developed a questionnaire for each of us at the meeting to 'interview' or talk to another member who we hadn't spoken to before. He said when talking to a new person, remember to gently construct questions by utilising your seven best friends, "Who", "What", "When", "Where", "Which" and "How". If we were uncomfortable doing the questionnaire with another member at the meeting, then it was requested members take the questionnaire away and complete with someone they whom feel less vulnerable and send or hand the completed questionnaire to Phil R at their earliest opportunity.

Phil R said the benefits that will result from interviewing each other will be:

- 1. We improve our skills in:
  - a. Communication.
  - b. Ability to read and interpret body language.
  - c. Confidence when socialising.
- 2. We will discover additional knowledge /ways to better understand ourselves and manage our PN. better.
- 3. We will help other members by sharing centralised knowledge.

Next meeting (August) is Crazy Clothes and Make a Total Fool of Yourself Day - \$50 Cash Prize for the craziest dresser:

Why? – Sometimes we just take ourselves too seriously and especially in the early hours of the morning, when pain is often at its worst, and we're unable to sleep we spend time feeling sorry for ourselves and possibly talking ourselves into depression. The solution is distraction by making a fool of ourselves, something to make us laugh when we recall the crazy /silly event later.

Who? – Every member attending. No pikers! Everyone must show up and participate.

When - August 2024 meeting.

Where – Passmore Room (our usual room at the Niche).

What /How? – Dress to shock (stay legal). Wear your worst matching clothes, go overboard, don't hold back, colour your hair, do what you dare wo, ho, ho.

Remember this is the type of activity where "the more you put in the more you get out". Barbara M and Faye H to judge the winner. (Judges and Phil R are ineligible to enter. If Barbara and Faye can't agree then Phil R will adjudicate).

The meeting closed at: 10:48 a.m.

Hey members! This is your newsletter so if you would like to see things added (or not covered) then you need to let Phil R know.

The next meeting is on Monday, 12th August 2024 at The Niche, cnr. of Hospital Avenue and Aberdare Rd, Nedlands W.A. 6009.

N.B. – Our annual subscription increases to \$20 as from 1/07/2024. Please pay promptly.

We rely upon donations to allow us to keep making improvements to our services for our members. A \$15 donation can go a long way.

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# PN COPING STRATEGIES QUESTIONNAIRE

### **Summary:**

The information below has been collected from our members to be shared for the benefit of all members. It is important to understand that what may suit one member may not suit another so therefore please consult your GP or healthcare professional to determine what is right for you.

## The purpose of this questionnaire is to:

- 1. Help find worthy additions to our PN arsenal in the form of our Coping with PN Document.
- 2. Then to anonymously share them with others in a similar position.
- 3. Improve our social skills by improving our communication skills (use questions that start with one of the following "who", "why", "what", "when", "which", "where" and "how").

Please complete the following questionnaire by yourself but preferably with someone you trust in an "interview" situation by letting the other person "interview" you.

Put a tick next to each item you're currently doing and write what additional things you're doing about the topic in each category. Feel free to write about new categories you've adopted.

- 1. Prescribed Medications (our No 1 weapon in our PN arsenal):
  - a. Opioids, Gabapentin, Paracetamol, Cannabis, Zostrix, Metformin, Lipidil Blood Pressure, Turmeric etc.
  - b. Swollen feet /ankles can add considerably to your overall pain level. Consider taking (with your doctor's ok) a diuretic (e.g., Furosemide belongs to a group of medicines called loop diuretics also known as water pills), others?
  - c. Moisturisers e.g. Restorate Foot Cream, Accident Cream etc. Moisturising can also reduce the severity of overall pain.

Contribute here:			
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2. Distractions: (our No 2 weapon in our PN arsenal)

Definition - Doing anything that takes your mind off the pain, 30 mins doing something is 30 mins not spent thinking about the pain. The more interested you are in the distraction the more effective the distraction is:

- a. The number and type of distractions is limited only by our imagination and preference.
- b. Act, Belong, Commit.
- c. Volunteer to one or more of the countless charities and support groups.
- d. Socialise and get involved with others of similar interests /purposes e.g. (but not limited to):
  - i. Beading.
  - ii. Quilting.
  - iii. Gardening.

- iv. Clubs.
- v. Friends.
- vi. Jigsaw puzzles.
- vii. Teaching /Lecturing (share your acquired knowledge with others).
- e. Play a musical instrument.

Contribute here:			
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- 3. Psychological (our No 3 weapon in our PN arsenal):
  - a. Treat /Reward Ourselves. Something small like a cup of tea /coffee to lift our spirits or maybe a little (or big) retail therapy.
  - b. We need to feel like we have adequate *control* over our situation after we are achieving points above and below in this questionnaire. If we are not feeling we have adequate *control* feelings of negativity, anger and desperation will result, this situation can lead to devastating outcomes. If this is where you're at then there's no shame in seeking help from a certified psychologist.

Contribute here:			
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### 4. Equipment:

- a. Footbath (iced or warm water, vibrating, water swirling action, etc.,). You can put your feet directly into the water or put your feet into a thin poly kitchen liner bag which allows most of the cold /warm to come through and with the option of wearing socks (with or without toes) to further control the amount of heat /cold the wearer feels.
- b. Use a medications container (Sun Sat, days of the week) to help you to remember to take your medications.
- c. Use phone /computer apps dedicated /appropriate to your condition e.g. blood sugar monitor.
- d. Use a quality brand blood pressure monitor with an appropriate app for your mobile phone and/or computer e.g. Omron.
- e. Use a smart phone to set up alarms to remind you to take medications.
- f. ONLY AS A LAST RESORT Walking Aids Mobility scooter /wheelchair, walking frame /stick, others?
- g. Bedclothes riser (to elevate bedclothes to avoid contact with feet /legs).
- h. TENS /EMS devices. Take care these devices stimulate nerves. In some cases of peripheral neuropathy your condition may be made temporarily worse by using stimulators as your condition may require relaxing not stimulating.

Contribute here:			
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## 5. Apparel:

- a. Compression socks (long, short, toeless).
- b. Comfortable shoes.
- c. Wear warm socks to bed.
- d. Wear short (summer)pyjamas as long legs rub on our ankles.

Contribute here:			
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- 6. Exercise (Neurologists recommend PN sufferers avoid stretching exercises):
  - a. Walking.

		Domestic duties (involving movement e.g. vacuum and mop floors etc).
	e.	Shopping.
Cont	ribute	e here:
7. N	Лedit	ation:
	a.	Listen to recordings (purchased media, online subscriptions etc.,) or foot tapping music or just music to help you relax.
Cont	ribute	e here:
8. F	amilv	and Friends:
	•	To non-PN sufferers there are no outward signs of PN only your behaviours of how PN affects you. Therefore, share how you are feeling as PN affects change multiple times during the day and night for the sufferer. Explain using terms to which the listener can relate e.g. PN feels like having the worst sunburn and intermittent toothache in your feet".
	b.	Supportive partner.
Cont	ribute	e here:
<i>9.</i> S	ocial:	
	a.	Make the effort to go out more than taking out your wheely bins.
	b.	Invite friends with whom you feel comfortable around to your place and go to theirs.
	c.	Get in the habit of staying busy.
Cont	ribute	e here:
10. F	Plans (	(If you fail to plan then you plan to fail):
	a.	Put together a plan to schedule and execute important and/or enjoyable activities. The first and

- foremost is your plan for effective sleep.
- b. Document "Your Daily Successes" into tables, spreadsheets, charts, notes etc. so you can easily compare your results to help direct you as well as keep you motivated.

Contribute here:			
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- 1. We can consistently do the same things and take the same medications and dosage every day, but sometimes we get different results. Some days you almost feel like you're cured and others you just want to call it quits.
- 2. Remember to share your results /ideas with other members of our group by sending /giving Phil R a copy of your completed anonymous questionnaire.
  - On a lighter note...

b. Cycling.

c. Mat exercises.



A lawyer defending a man accused of burglary tried this creative defence:

"My client merely inserted his arm into the window and removed a few trifling articles."

His arm is not himself, and I fail to see how you can punish the whole individual for an offense committed by his limb."

"Well put," the judge replied.

"Using your logic, I sentence the defendant's arm to one year's imprisonment.

He can accompany it or not, as he chooses."

The defendant smiled. With his lawyer's assistance, he detached his artificial limb, laid it on the bench, and walked out.

Consider this...

- I took my suit to the cleaners, who wanted to charge me \$40, so I gave it to the charity shop next door. They cleaned and pressed it and put it in the window. I bought it back for \$15.
- 2. My wife said: "That's the 4th time you've gone back for dessert! Doesn't it embarrass you?" I said: "No, I keep telling them it's for you."
- 3. When I was in high school, we learned about a shape called a rhombus and that was the last time I ever heard about that shape.
- 4. My wife and I started role-playing in the bedroom. Her favourite is The Sexy Librarian where I must lay quietly while she reads a book.
- 5. Being old is when you don't care where your spouse goes, just as long as you don't have to go too.
- 6. I now know how it will all end for me, one of my grandkids will unplug my life support to charge their phone.
- 7. At a wedding reception, someone yelled: "All married people please stand next to the one person that has made your life worth living." The bartender was almost crushed to death.

BEING KISSED
WHILE YOU'RE
ASLEEP IS ONE OF
THE PUREST
FORMS OF LOVE...
UNLESS YOU'RE IN
PRISON.