Last Update: 6/08/2025

PN COPING STRATEGIES QUESTIONNAIRE

Summary:
The information below has been collected from members to be shared for the benefit of all members. It is important to understand that:

1. What may suit one member may not suit another therefore talk to your GP or healthcare professional to determine what is right for you.
2. We each have a body a brain and a mind. It is vital all three are in sync with each other. Research and apply the tools necessary to help understand, apply and achieve synchronisation.

The purpose of this questionnaire is to:

1. **Help us find worthy additions to our PN armoury.**
2. **Then to anonymously share them with others in a similar position to us.**
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").**

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. Probably as important as medication itself is determining whether you need to take your medication proactively i.e. every 4 hours regardless on pain level or reactively i.e. only when pain passes a tolerable level. If you can rely on taking your medication reactively so much the better however you need to take into consideration the latency i.e. the time medication takes to kick in.
    c. 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?
    d. Non-prescription medications: Metsol (heat rub).
    e. Moisturisers e.g. Restorate Foot Cream, Accident Cream etc. Moisturising can also reduce the severity of overall pain.

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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.

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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.
   c. Words are very important. Our brain and mind is a fantastic instrument. There is very little that it can't achieve. Therein lies an inherent problem.
      We each need to be very careful of the words we say to ourselves For example: If I say to myself the pain of peripheral neuropathy is more prevalent at night then the brain and the mind will make it happen. If I say to myself "when the sun goes down the pain comes up" the brain and the mind say "OK… if that's what you want, then I'll make it happen". Over simplistic? Maybe so but why take the risk when there's nothing to be gained and our quality of life will suffer?
      OK well how do we stop the flow of negative words and thoughts? Psychologists have said that positive mental attitude is nothing more than a habit and like most habits they can be made or broken within 21 days of determination and commitment (I'm not talking about illicit drugs here as I have no experience in that field).

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4. *Equipment:*
    a. Footbath (cool or warm water (but never ice) 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 cool /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.
    Alternatively try this convenient and portable way to temporarily cool your pain.
    Purchase a couple of gel packs (they're available from Woolies and sold in packs of two). Once cooled (but not frozen) they can be placed on a suitable surface on a small hand towel or in a suitable receptacle e.g., your footbath. You don't have to add water just rest your feet on the cooled /warmed gel packs. Try not to put too much weight on the gel packs as they will split, and the gel will leak out.
    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. Rebuilder (7.83 Hz), TENS and/or EMS devices. Take care these devices stimulate nerves. In some cases of peripheral neuropathy your condition may be temporarily worsened by using stimulators as your condition *may* require relaxing not stimulating.
    i. Infrared Light Therapy. Strap-on low level heating units applied to legs and feet to help control pain by improving blood circulation.
    j. Go to a pediatrist regularly and or use good quality foot file (not razor blade) to remove hard skin (not too much) from feet and hard skin /pressure points can increase foot discomfort.
    k. Vibrating Platform. Essentially, it's small platform that wobbles from side to side. Its purpose is to help tone your body and to help improve blood circulation thus delivering more blood to damaged nerve ending and possibly repairing them. Your can sit on the platform or stand on it for the more adventurous.

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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.

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6. Exercising (Some Neurologists recommend PN sufferers avoid stretching exercises whilst other encourage stretching):
    a. Walking.
    b. Cycling.
    c. Floor /mat exercises.
    d. Domestic duties (involving movement e.g. vacuuming and mopping floors etc).
    e. Shopping.
    f. Frequent movement /Changing sitting position. Maintaining a sitting position can result tingling sensations implying nerve compression is occurring in the lower back, buttocks and/or upper legs. Tingling/ pins and needles appears to be the body's way of telling us that something needs to change in the very near future. Therefore, as soon as we are aware of these sensations We consider getting up and moving around until the sensations are gone.

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7. *Meditation:* Listen to recordings (purchased media, online subscriptions etc.,) or foot tapping music or just music to help you relax.

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8. *Family and Friends:*
    a. 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, wearing socks made from steel wool (pot scourer) and just to round it off intermittent toothache in your feet".
    b. Your partner. If he /she seems less than supported:
        i. When explaining how PN is affecting you physical and emotionally it's important you use your own words if you wish to come over as authentic. Pick a good time and make sure you're in a friendly mood, feeling like an "equal" and talking in an "adult" manner. Take your time and don't rush or get tensed up. Speak in a relaxed pace and image you're talking about your best friend. Most importantly don't let your relationship with your partner "get in the way" of what you're trying to achieve and that is you want to gain understanding and support. At this point in time, you need a "coach" and not a "critic".

            Avoid becoming defensive or arrogant (which is another form of defensive) if you get agitated his /her arms will fold and his /her "brick wall" will go up.

        ii. If you could see my nerve endings in my peripheral extremities, you would see that they are damaged and/or the insulation around the nerves (myelin sheath) is damaged.
        iii. I understand why you would think or say that PN is all in my head. But just think about that for a while isn't everything in our head? it is only our senses (including our touch) where our nerves send a signal to our brain that keeps us in touch with what we call is reality?
        iv. Please also listen with your eyes as well as your ears and you will see that my face is showing pain, and my gait is less than normal.
        v. (If applicable say) Take a look at the discoloration in my legs and feet. Is the colour of mine the same as the colour of yours?
        vi. Please help and support me by doing a bit of research on the Net on PN.
        vii. It is suggested you use one or a small number of the points above and don't try to bring about radical change in your partner in a short time. Keep in mind that it takes time for others to be able to update their perception of you.

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9. *Social:*
    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.

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10. *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.

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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 totally 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 questionnaire*.