



NOTES FROM THE NEUROPATHY SUMMIT

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Agenda

- Information about Conference and The Neuropathy Association
- Why does Neuropathy Matter?
- Why are Symptoms So Different?
- What is the Latest on Treatments and Research?
- What Can This Support Group Do?

Information About the Summit

- The Neuropathy Association
 - 50,000 members, 135 support groups, 15 centers of excellence
 - Mission: awareness, education, support, advocacy research
 - 5 staff members, Board, Medical Directors
- The Summit
 - First conference of its type ever, 400 in attendance
 - Purpose:
 - Discuss the state of peripheral neuropathy care and treatment today
 - Advance our education about a multi-disciplinary approach to neuropathy and neuropathic pain
 - Call for greater awareness and understanding for this greatly underappreciated illness
 - Focus on pain

Why Does Neuropathy Matter?

- 10-14% of the population over 40 has neuropathy. 20 million people in US alone
- Neuropathy is a leading cause of disability due to pain, gait problems and foot ulcers. Estimated \$3.5 B in health care costs annually.
- Pain - 8% of world population has neuropathic pain. There are 6M neuropathic pain sufferers in US alone.
- 15-20% of cancer patients develop neuropathy.
- 40,000 amputations each year related to neuropathy

Why Does Neuropathy Matter?

- Prevalence Rates

| Disease | Prevalence in U.S. |
|---------------------|--------------------|
| Multiple Sclerosis | 250,000-350,000 |
| Parkinson's Disease | 1 million |
| Alzheimer's Disease | 5.2 million |
| Breast Cancer | 2.5 million |
| Neuropathy | 20 million |
| Diabetes | 23.6 million |

- Why is this so?

Causes of Neuropathy

- > 150 causes for neuropathy
 - Acquired – diabetic
 - Nerve compression
 - Entrapment
 - Inherited disorders,
 - Deficiency states - vitamin
 - Exposure to toxins
 - Metabolic dysfunction
 - Inflammation
 - Idiopathic – 30% of patients
- Neuropathy classified by the following:
 - Course of onset – acute, sub-acute or chronic
 - Part of nerve targeted – myelin or axon
 - Which fiber is affected – motor, sensory, autonomic or combination

Why Are Symptoms So Different?

| Nerve Fiber | Size | Symptom |
|-------------|----------|--|
| Motor | Large | Weakness, twitching, cramps, numbness |
| Sensory | Small | Numbness, tingling, itching, burning |
| Autonomic | Smallest | Sweat, incontinence, lack of digestion |

- Which nerve fibers are damaged and to what degree determines symptoms

Types of Neuropathy

- Chronic Axonal, Length Dependent Polyneuropathy – Diabetic, B-12 deficiency, Idiopathic
- Inflammatory – GBS, CIDP, MMN
- Polyradiculopathy – damage to the nerve roots
- Mononeuropathy Multiplex – damage to the large nerves all at once.

Current Treatment of Neuropathy and Neuropathic Pain

1. Reverse or slow neuropathy

- Acquired – glucose control, improve circulation in diabetics
- Autoimmune – IVIG, steroids, Plasmapheresis, Immuran, Cellcept, Rituximab, stem cell transplant
- Metabolic dysfunction – reversal of dysfunction i.e. renal insufficiencies
- Infectious - antibiotics
- Vitamin Deficiency- treat deficient state i.e. B-12
- Toxic – removal of exposure to toxin i.e. lead, B-6

Current Treatment of Neuropathy and Neuropathic Pain

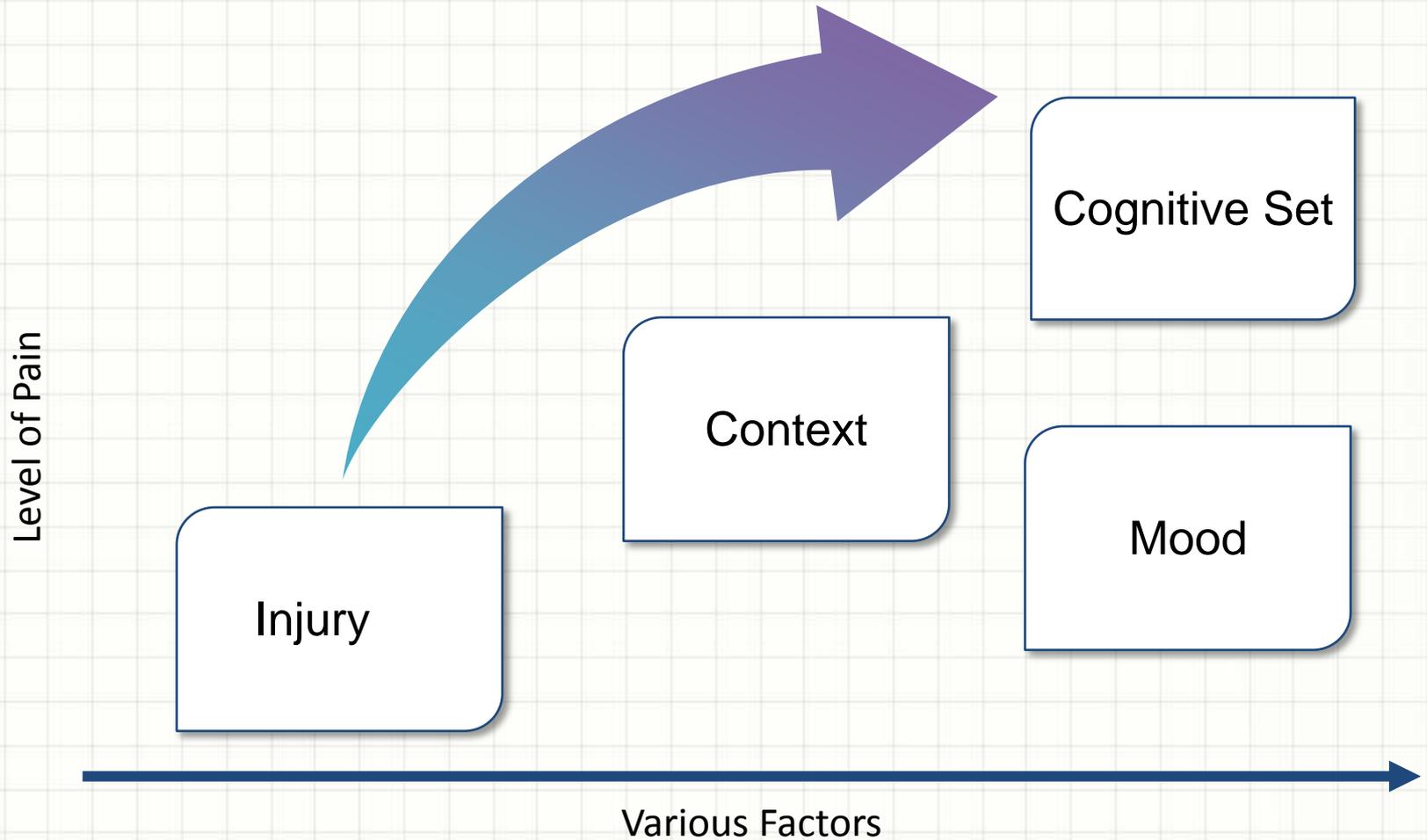
2. Treat symptoms

- Pain
- Muscle weakness
- Gait imbalance
- Sensory impairment
- Mood dysfunction

Treatment of Neuropathic Pain

- Principles of Pain Management
 - Complete pain relief is uncommon. The goal is to decrease it by 30-40%. This is considered a good response. Measure how well the pain medication is working by whether you meet this goal.
 - Response to pain medications is highly individual & difficult to predict
 - Titrate up if the response isn't good enough – greatest reason pain medication doesn't work is you stopped it too soon at too low of a dose. Avoid premature discontinuation unless the side effects are intolerable.
 - Match drug choice with the risk/benefit ratio and adverse event profile
 - Proper dose varies among patients
 - Effectiveness all depends on proper dialogue with your physician.

Pain and Neuropathy



Treatment of Neuropathic Pain

1. 1st Line drugs – Neurontin, Lyrica
2. Cymbalta, nortriptyline, amitriptyline, tramadol (altram). Good for mild pain. Effective by itself. 50 mg every 4-6 hours is effective at night time to get through the pain.
3. Lidoderm patches. Not as effective. Better for specific area
4. Capsaicin – pepper cream. Effective if you can get through the initial pain of it.
5. Opioids – for refractory pain
6. Anticonvulsants. This is an add-on therapy and by itself inadequate.
7. Spinal Cord Stimulator (SCS). May give partial relief to patient who has refractory pain. Up to 50% pain relief. This is also an option if using opioids.
8. Neurolysis – destruction of nerves. For mononeuropathy only.
9. Non-pharmacological pain treatment – putting feet in ice. Don't do this as temporary relief as it damages the small nerve ending in the feet and sets you up for longer worse recurring pain.

Current Treatment of Neuropathy and Neuropathic Pain

- Experts do not know how to make nerves regrow yet.
- Prevention is better than cure
 - Strict control of diabetes and glucose
 - >140 and ≤ 200 can be cause of neuropathy
 - Decrease high BP, lipids and weight
 - Stay away from toxins
 - Assess and handle nutritional deficiencies
 - Treat alcoholism
 - Treat viral infections
 - Immune system modulation

Current Treatment of Neuropathy and Neuropathic Pain

- Immune System Modulation
 - Metanx – a medical food, a nutritional supplement FDA approved for diabetic neuropathy.
 - Alpha Lipoic Acid – Free radical scavenger. Most studies have been with diabetic neuropathy
 - Acetyl-L-Carnitine – for diabetic neuropathy. Two studies show improvement in pain as well as changes in nerve conduction studies.
 - Neuro-V – supplement. For diabetic, chemo-induced and auto-immune
 - Capsaicin – topical agent that depletes nerves of substance P. Can be beneficial. Dose .075-.10%

Current Treatment of Neuropathy and Neuropathic Pain

- Other Treatments

- MIRE Therapy – infrared light therapy which releases nitric oxide because it allows more blood flow to get to the nerves.
- FREMs – electrical signal through electrodes. Improves blood flow to the nerves.
- Surgical Decompression – Decompress nerves to increase blood flow. No studies on this yet. Data limited in efficacy.

Current Treatment of Neuropathy and Neuropathic Pain

- **Communicating about Neuropathy**

Talking about pain and weakness are complex, but improving communication can have positive benefits

- 2006 study on pain and loved ones
- Holding back from talking about pain caused more pain

Where is the Research Heading?

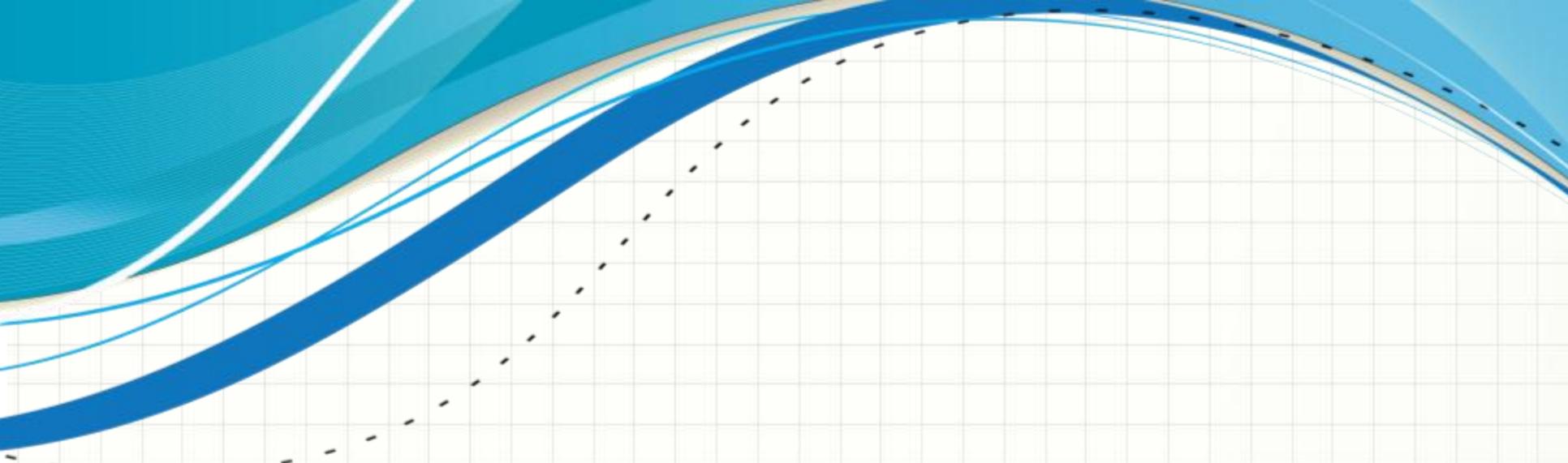
- Regeneration of nerves to restore function and health
- Inherited neuropathies – help to teach about myelin proteins and how myelin and axon work together
- Underlying cause of the neuropathy – genetic based studies, chemo-induced neuropathy studies
- Changing immune system

What Can This Group Do to Help?

- Support The Neuropathy Association's efforts
- Promote education and awareness in Austin
- Become knowledgeable about current research and clinical trials (www.clinicaltrials.gov)
- Support each other, talk about the pain and the successes of living with neuropathy.

Summary

- Neuropathy needs greater awareness and understanding in order to get the resources needed to find cures.
- Treatment today is to slow neuropathy and address symptoms.
- Treatment tomorrow focuses on nerve growth and healthy immune systems.



QUESTIONS?