



FIBROMYALGIA
AOTEAROA NZ

FIBROMYALGIA.ORG.NZ

Intro to Fibromyalgia:

UNDERSTANDING FM & MANAGEMENT APPROACHES

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Agenda

- ▶ Introduction (15 mins)
 - ▶ Using Zoom
 - ▶ What is FMNZ all about
 - ▶ Group rules/ safe space
- ▶ Whakawhanaungatanga (10 mins)
 - ▶ Getting to know eachother
- ▶ Curriculum topic (25 mins)
 - ▶ Understanding fibromyalgia & your diagnosis
- ▶ Facilitated discussion (20 mins)
- ▶ Reflection (20 mins)



Using Zoom

- ▶ Technical issues / troubleshooting?
- ▶ Zoom etiquette / tools
 - ▶ Mute your mic unless you're speaking
 - ▶ Improves sound quality for everyone
 - ▶ Use the chat function if you'd like to go next
 - ▶ Indicate what you'd like to talk about
 - ▶ Possible to hide video
 - ▶ Chat for any extra info/ resources
 - ▶ Will post on Facebook/ website afterwards



About FMNZ

Mission

Supporting people to **be well** with Fibromyalgia.

Supporting our **society** to be more responsive and accessible for people with chronic illness.

Approach

We believe that all people with chronic illness should be able to access appropriate and effective support to manage their conditions.

- Affordability
- Accessibility
- Evidence based

Services

Support groups

- In person
- Online

Targeted Facebook groups

Information and resources

- fibromyalgia.org.nz
- Facebook page

Advocacy



Group Rules / Safe Space

- ▶ Mutual respect
- ▶ Non-discrimination
- ▶ Medicinal cannabis - keeping group conversations safe
- ▶ Medication
 - ▶ Support not medical advice
 - ▶ “Something that worked for me...”
- ▶ Confidentiality
 - ▶ Can share information/ techniques you’ve learnt from the presentations
 - ▶ Don’t share other people’s stories or personal information
 - ▶ People are more identifiable than you may think
- ▶ *Any additions?*



Whakawhanaungatanga

2 MINS MAX

- Who you are
- Experience with fibro
- What you want to get out of this
- Something interesting about you



Understanding Fibro

- What is fibro
- What does the diagnosis mean for me?
- Management approaches



Understanding fibro

- ▶ What is fibromyalgia?
 - ▶ Symptoms - chronic, syndromatic
 - ▶ Pain
 - ▶ Fatigue
 - ▶ Cognitive impairment
 - ▶ ... and many more
 - ▶ Cause
 - ▶ Still being researched
 - ▶ Central sensitisation ?
 - ▶ Inflammation ?
 - ▶ Treatment
 - ▶ Nutrition and exercise
 - ▶ Psychological approaches like CBT
 - ▶ Physiotherapy
 - ▶ Pharmacotherapy



Understanding your diagnosis

- ▶ Everyone's fibromyalgia is different
 - ▶ Sometimes unpredictable
 - ▶ Sometimes predictable
- ▶ Your symptoms and experience is valid
 - ▶ You don't need other people to affirm that your experience or pain is real
- ▶ Lifelong journey
- ▶ Grieving process
 - ▶ Allow yourself time and space to grieve
- ▶ Support people
 - ▶ Open dialogue
 - ▶ Different approaches for different people
 - ▶ People not being able to give support isn't a reflection on you



Before strategising...

General reflection points

- ▶ What symptoms are the most severe?
 - ▶ What am I most bothered by?
 - ▶ Do certain activities exacerbate/improve?
 - ▶ Can I modify this?
 - ▶ What are my own limitations?
 - ▶ What are things I am willing to compromise on?
 - ▶ What are things that I **am not** willing to compromise on?
-
- ▶ Abundance mind set and positive self talk
 - ▶ You are not your diagnosis
 - ▶ Address guilt & dependency
 - ▶ Rome wasn't built in a day!



Approaches for management

- ▶ Managing symptoms
- ▶ Managing triggers
- ▶ Managing underlying causes
 - ▶ Sleep
 - ▶ Nutrition
 - ▶ Movement
- ▶ Different approaches will work for different people



Strategies for management

Specific tools

- ▶ Symptom /pain journal
 - ▶ Can help add perspective and reveal triggers
 - ▶ But risk becoming overly focused on negative
 - ▶ Use sparingly
- ▶ Trigger management
 - ▶ Can be very helpful in acute situations
 - ▶ Ensure not overly self-limiting
- ▶ Pacing
 - ▶ Find a balance where you are still able to do things that you love and that are important to you



Facilitated Discussion

- What is our current understanding?
- Does anything conflict?
- What do we want to understand better?
- What do we already do to manage?
- What do we struggle with?
- What has worked well?



Reflection

2 MINS MAX

- What did you find helpful?
- What are you grateful for?
- What are you looking forward to?