

# What Recovery Can Look Like

Prepared by Tracey Larsen



For many people living with ME/CFS/FM, they dream of 100% recovery, but with Chronic Illness this is sometimes not possible and can be an unrealistic target.

Seeing “recovery” as being an improvement in your health to a point where you can live a productive, fulfilling life is a great goal to aim for. Some may be able to return to work, part time or full time, or find other meaningful ways to contribute to their family and society on a consistent, committed basis.

Many report that their life is more meaningful now, than prior to their illness and they live more authentically.

Many report that their functioning levels are not at 100%, but more realistically at 75-80%.

Where are you on your journey?

Where have you been?

Where are you now?

## The ME/CFS & Fibromyalgia Rating scale

- |     |   |
|-----|---|
| 100 | Fully recovered. Normal activity level with no symptoms   |
| 90  | Normal activity level with mild symptoms at times   |
| 80  | Near normal activity level with some symptoms   |
| 70  | Able to work full time but with difficulty. Mostly mild symptoms  |
| 60  | Able to do about 6-7 hours of work a day. Mostly mild to moderate symptoms  |
| 50  | Able to do about 4 – 5 hours of work a day, or similar activity at home. Daily rest required. Symptoms mostly moderate. |
| 40  | Able to leave the house up to 5 days per week. Moderate symptoms. Physically active 3 – 4 hours a day                   |
| 30  | Leave the house several times a week. Moderate to severe symptoms. Active 2 – 3 hours a day.                            |
| 20  | Leave house once or twice a week. Moderate to severe symptoms.  |
| 10  | Leave house occasionally. Severe symptoms   |
| 0   | Bedridden. Unable to care for self.   |

How does today's rating compare to when you were first ill? The 2<sup>nd</sup> year? Last year? Have you seen your illness rollercoaster up and down? Steadily improve? steadily decline?

## Members Meeting Resource

### **Raelan Agle – 20 personal stories of recovery**

<https://www.youtube.com/watch?v=kX6zyGDGKrl>

Raelan has recovered from her own experience of ME/CFS. She has created a lot of video clips on you tube, sharing her own journey to recovery. She has also interviewed many others who share their stories too.

In the link above she brings together the key themes of everyone's stories that was instrumental in their recovery.

#### 1. Mindset

Everyone speaks of a belief that they can recover. They held determination and a refusal to not give up. However, they spoke of how the journey was not linear and they allowed depression to walk beside them in their journey. They still experienced peaks and troughs but never gave up.

#### 2. Pacing

It was important to get out of the boom-and-bust cycle. Acceptance of their limitations was key!

#### 3. Stress Management

Getting stress under control. Relaxation practices and meditation were some of the strategies used to bring a state of calm to their lives.

#### 4. Recovery-focused

Made themselves number one priority in their lives. Deprioritised outmoded ideas/habits/relationships

#### 5. Listen to their own intuition/gut instinct

They followed ideas that resonated with them. There are many ideas, diets, supplementation, programs on offer that can be followed. Raelan speaks of the small fortune she spent seeking "the magic bullet". All her interviewees spoke of listening to the different ideas, but ultimately followed only the ones they resonated with.

Raelan speaks of the many paths her interviewees took, which highlights the need for a holistic approach.

What they did NOT do was rest their way out of ME/CFS. Yes, rest is an important component, but total rest made them feel worse. Sometimes short-term total rest is required, for a few days, but not for weeks or months on end.

Hope alone also did not work. Action is required!

## Members Meeting Resource

The holistic approach that was a common theme among the interviewees were:

- Diet – some followed vegan, plant based, keto, paleo, anti-inflammatory diets, carnivore diets
- Gut health – supplementation, fasting
- Energy medicine
- Ayurveda/Indian medicine
- Movement - increase slowly as able
- Healing trauma's/counselling/psychologist involvement
- Healing mould toxicity/detoxing
- Relaxation strategies
- Living more authentically

### Shannon Emelia - 2020 Chronic Fatigue Syndrome Year Review (My recovery story) 10% to 60%

[https://www.youtube.com/watch?v=ef7x\\_uVOPVM](https://www.youtube.com/watch?v=ef7x_uVOPVM)

In this video Shannon describes her year, month by month of her progress from 10 % functioning in January 2020 to 60% in December 2020 . What she highlights is that throughout the year her energy and activity levels yoyo a little bit but ultimately, she sees a steady improvement throughout the year.

At the 18 minute mark of this video she lists three things that she credits to her increase in the rating scale from 10% in January 2020 to 50% by October 2020.

**Diet** – paleo/keto diet

**Vitamins and mineral regime** – Daily doses of B12, Vit C, Di ribose, Magnesium, CQ10, Hemp seed oil, B3, Vit D, Multi mineral supplement, (8.39mins into video)

**Pacing**

Supplement regime as prescribed by Dr Sarah Myhill.

#### References

R. Agle (29 June 2021). Chronic Fatigue Syndrome - How 20 people Fully Recovered  
<https://www.youtube.com/watch?v=kX6zyGDGKrI>

Rating scale. The ME/CFS & Fibromyalgia Self-Help Program  
<http://www.cfselfhelp.org/cfs-fibromyalgia-rating-scale>

S. Emelia (21 January 2021). 2020 Chronic Fatigue Syndrome Year Review (My recovery story) 10% to 60%.

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