

Fatigue Management in Haemochromatosis



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Why am I experiencing Fatigue?

Organ Dysfunction:

Iron overload strains organs (e.g., liver, heart), reducing their function and causing tiredness

Joint/Muscle Pain:

Iron deposits can lead to aches, stiffness, and physical fatigue

Hormonal Imbalances:

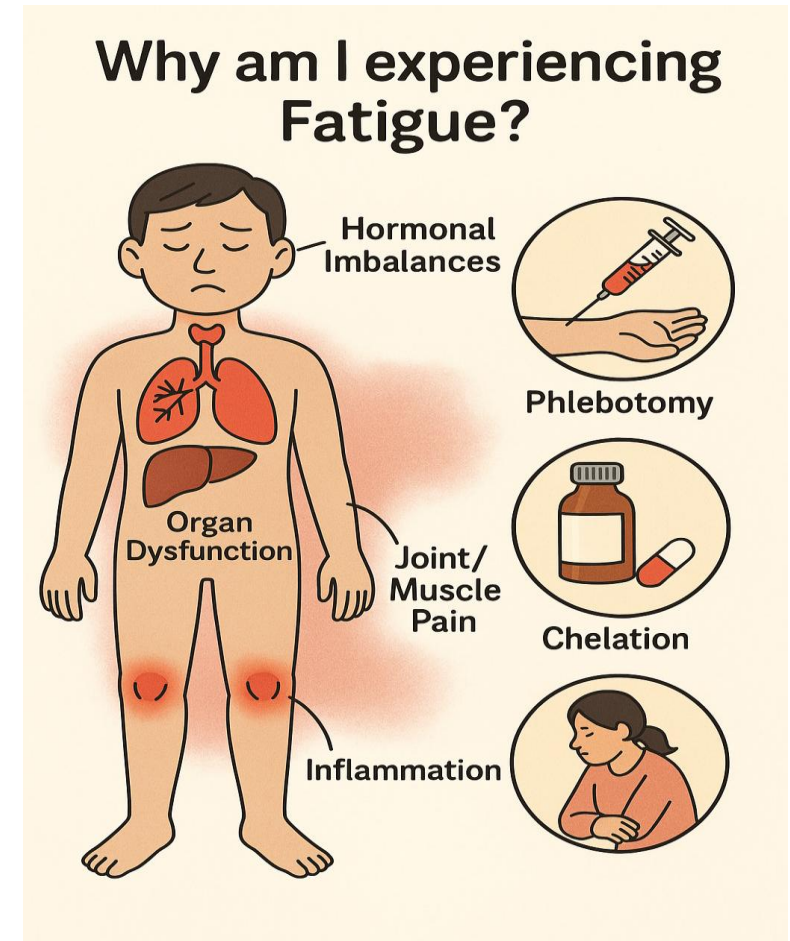
Iron affects glands (like the thyroid), disrupting hormones that control energy and mood

Inflammation:

Ongoing inflammation from iron buildup can worsen fatigue

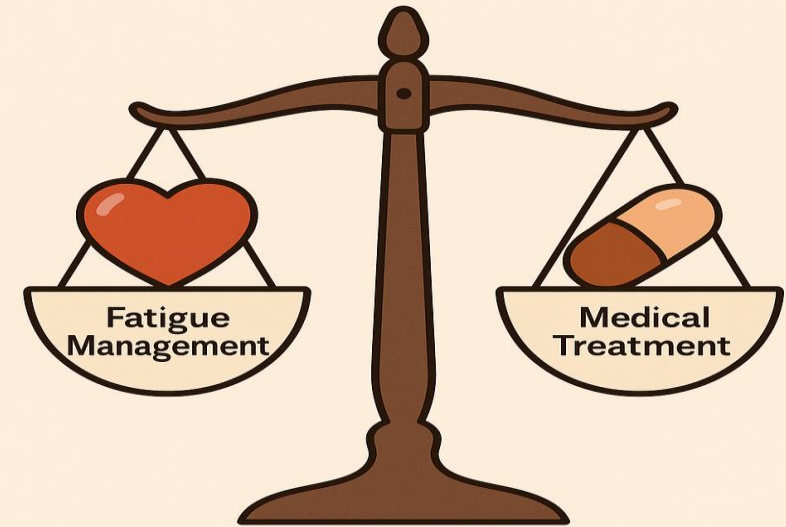
Phlebotomy/Chelation (Short-Term):

These treatments may temporarily cause tiredness as the body adjusts



Fatigue & Treatment: Striking the Right Balance

- Fatigue is a common, persistent symptom of haemochromatosis
- Managing iron overload is crucial
- Balance medical treatments with fatigue management and personal needs



Haemochromatosis & FATIGUE

- Extreme state of tiredness
- Exhaustion
- Lethargy
- Ongoing



Haemochromatosis & FATIGUE

- Appears more **suddenly**, lasts **longer**, and **difficult to recover**
- **Hidden / invisible**
- **Common and real**
- **Affects 75-80% of those living with haemochromatosis**

**“A crushing
tiredness that no
amount of sleep
fixes”**

**“Invisible to
others but
dominating my
day”**

**“Like wading
through mud—
you’re exhausted
before the day
begins”**

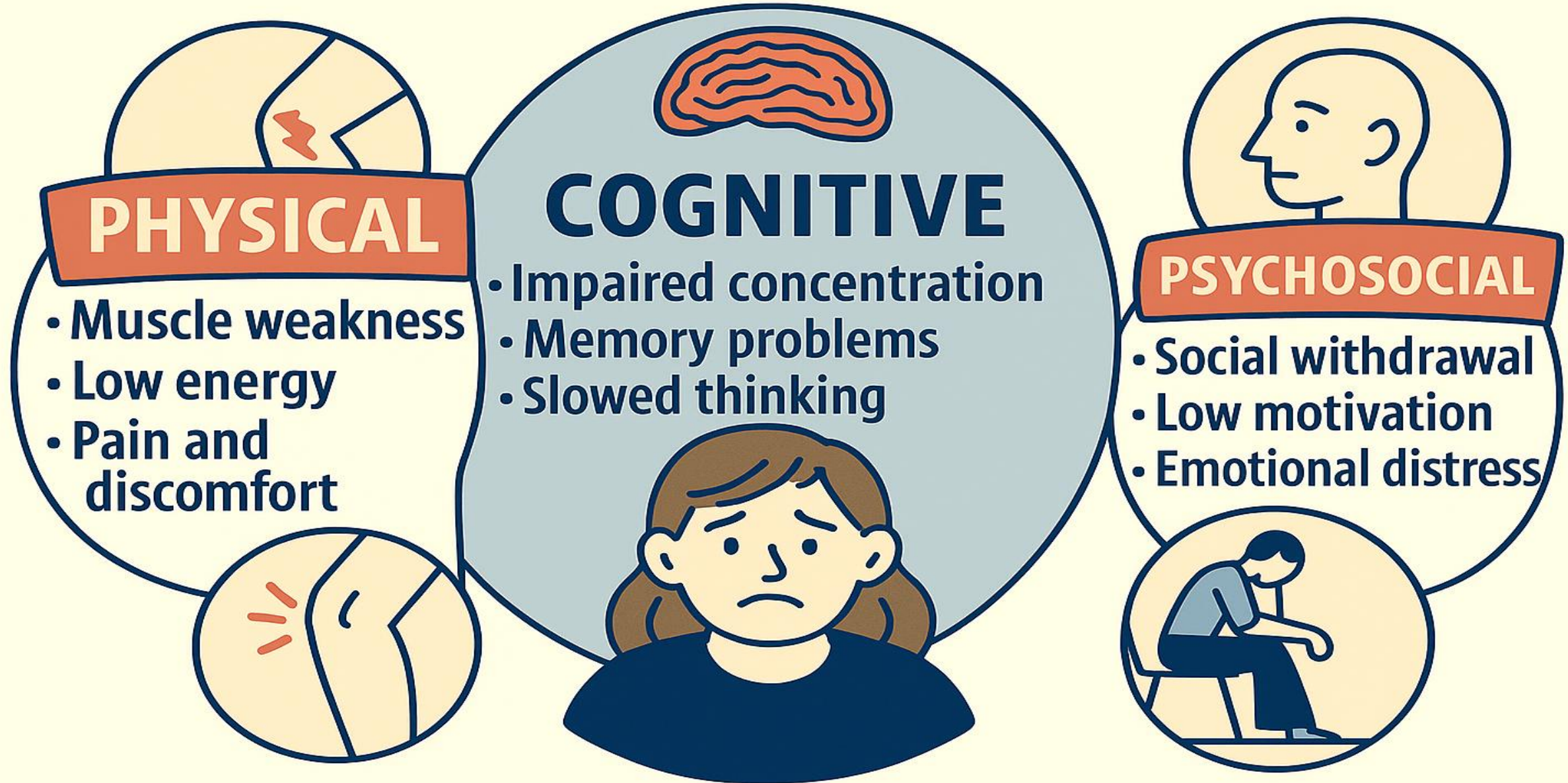
Impacts of Haemochromatosis & Fatigue

Different impacts

Some are **physical** – Easily recognised

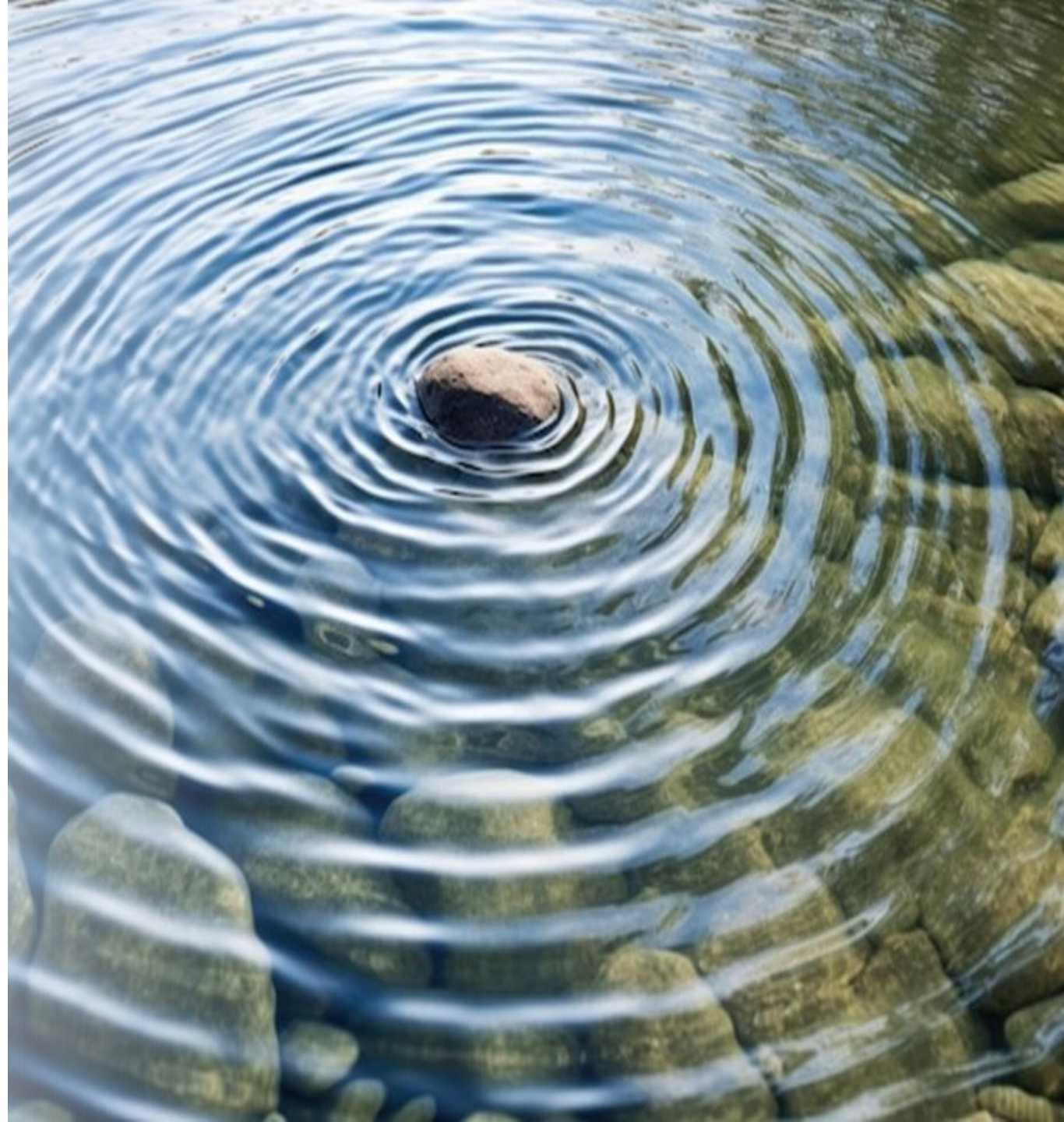
Many are **hidden** - cognitive and psychosocial

THE MANY FACES OF FATIGUE



The Ripple Effects of Fatigue

- Feeling misunderstood
- Mental health impacts (e.g., anxiety, low mood)
- Identity and self-esteem challenges
- Reduced independence
- Work related difficulties
- Social isolation
- Role changes within the family
- Intra / Interpersonal relationship difficulties

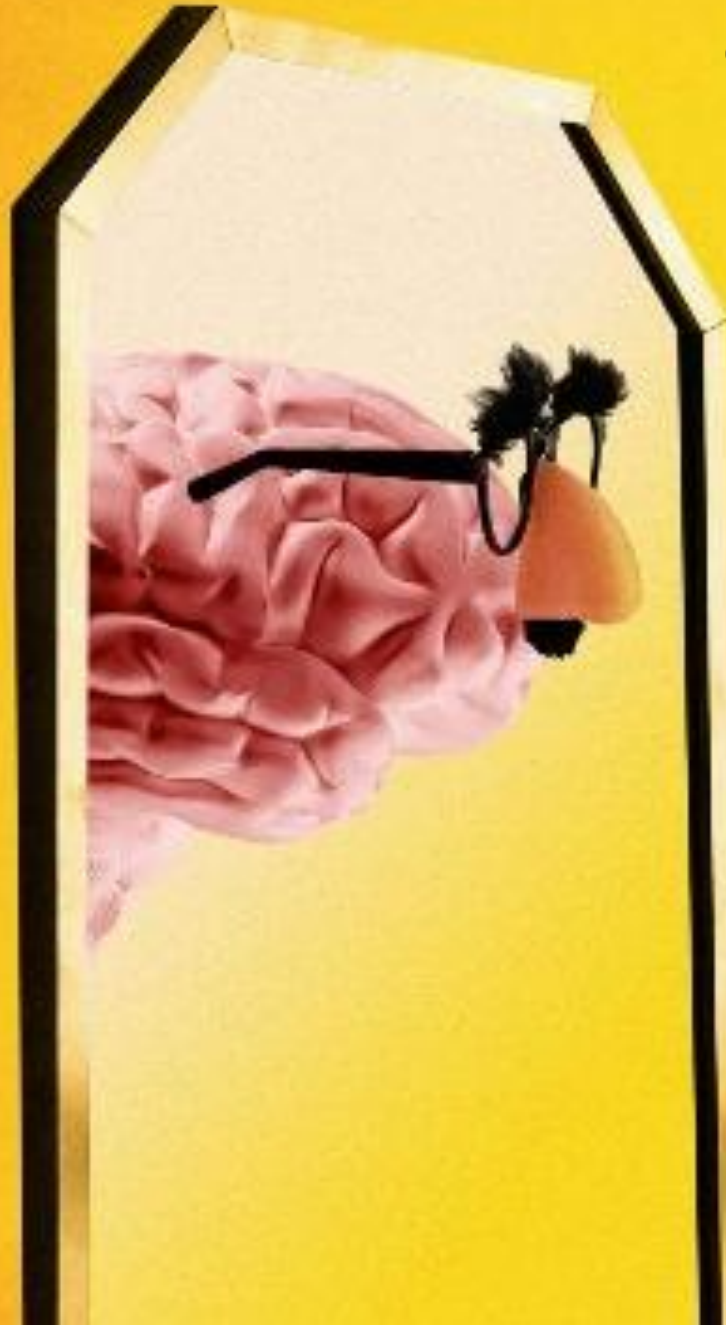


Living with Fatigue: What You Can Do!

- Fatigue is often described as one of the most disabling symptoms
- It can persist even after iron levels are reduced
- This highlights the need for ongoing coping strategies



GET TO KNOW YOUR FATIGUE



**10 FATIGUE MANAGEMENT
STRATEGIES**

1) GETTING TO KNOW YOUR FATIGUE



A fatigue diary rates daily activity, rest, cognitive symptoms and fatigue levels



Helps determine patterns of behaviour that contribute to fatigue

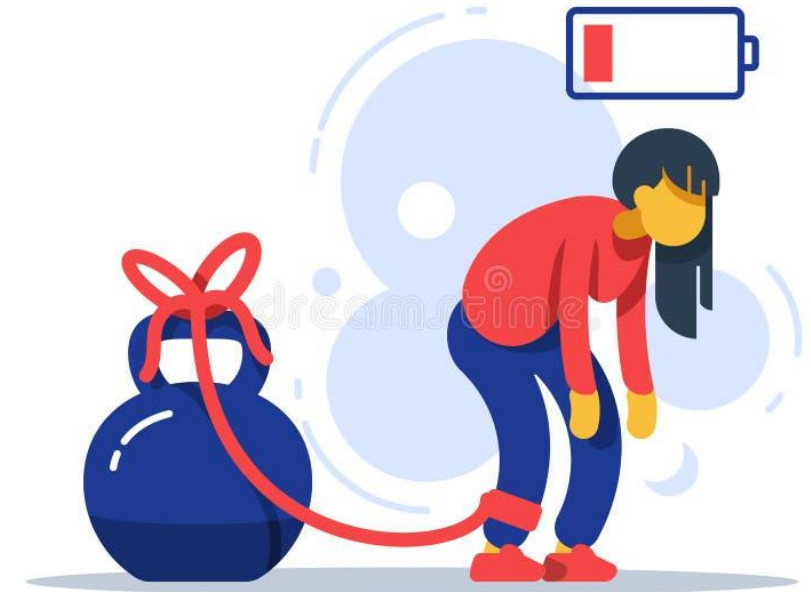
Fatigue Diary

Date: 23/01/24

Sleep	I slept really well. The alarm went off at 8 o'clock and I felt good. I had a lot of energy.		
Time	Activity	Fatigue Score	Comments
9am	Easy run around the park	2	Felt good
11am	Attended public event	5	Felt anxious
3.30pm	Returned home from event	9	Felt drained
4pm	Had a nap	2	Felt better and calmer

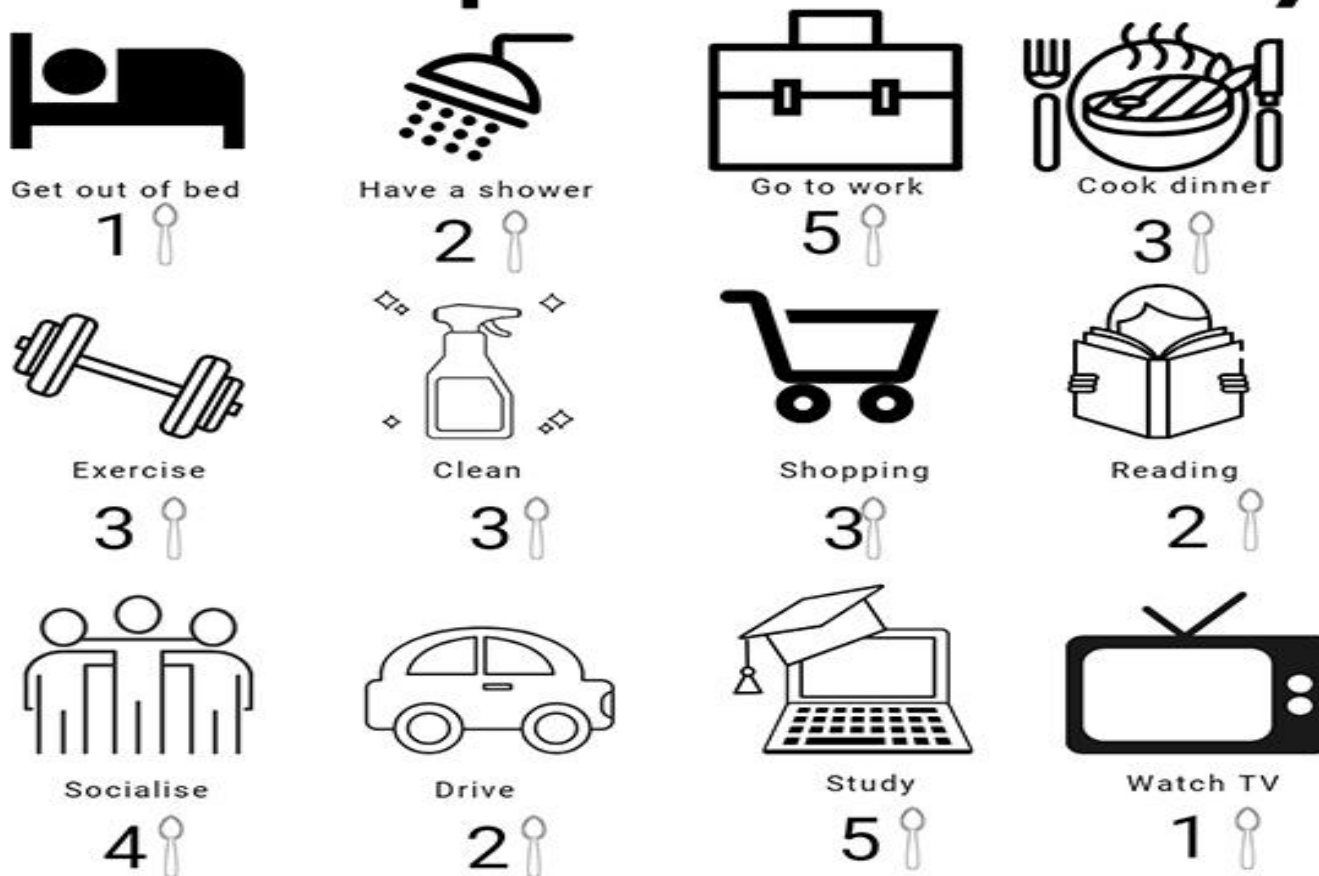
UNDERSTANDING YOUR FATIGUE DIARY

- Look at your routine
- What fatigues you?
- What time do you function best during the day?
- Prioritise difficult tasks during these times
- Seek support



2) MANAGE YOUR DAY

The Spoon Theory



You have 12 spoons per day – how will you use them?

If you use more, you take a spoon from the following day starting the next day with a deficit

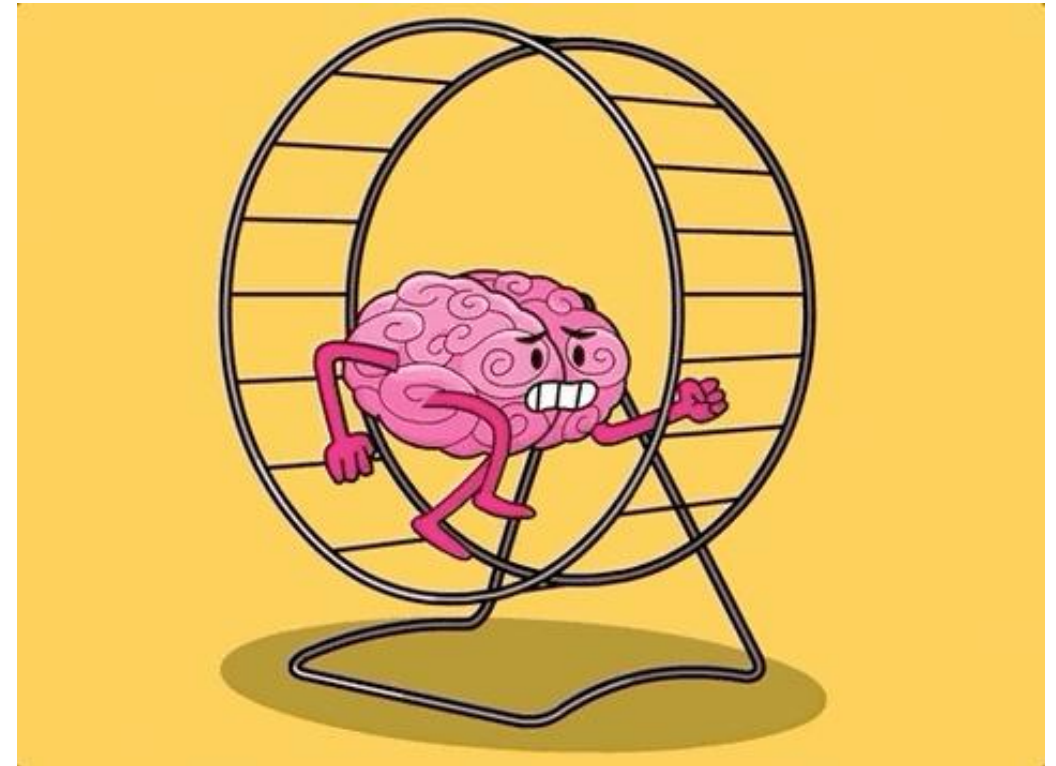
3) EMPTY YOUR STRESS BUCKET



**KEEP SOME
SPOONS
FOR FUN
ACTIVITIES
THAT
NOURISH
YOU AND
BRING YOU
JOY**

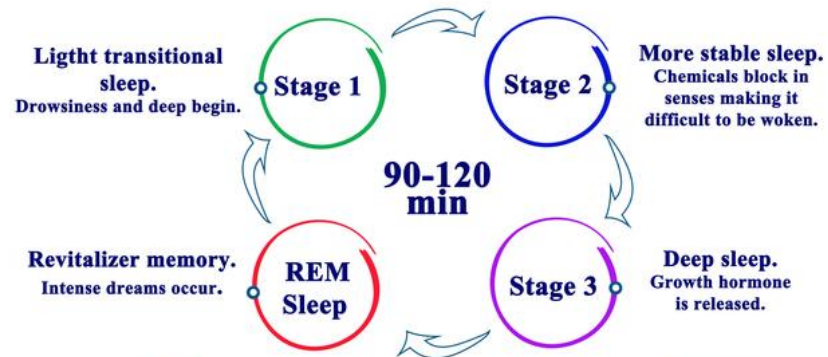
4) REST

- **Battery drains faster**
- Take **regular rest breaks**
- **Pace activities**
- **Break down** activities into a series of smaller tasks



NAPPING

Sleep Cycle Stages



✓ **10-20 Minute Nap** - Good for quick energy boost

✓ **90 Minute Nap** – Good for deeper rest and memory

✓ **Early in the day (1-3pm)**

5) MINDFULNESS

CHOCOLATE MEDITATION (EATING MINDFULLY)

SIT COMFORTABLY, AWAY FROM DISTRACTIONS.

TAKE A PIECE OF CHOCOLATE IN YOUR HAND.

REALLY LOOK AT IT.

FEEL ITS WEIGHT AND TEXTURE.

LOOK AT ITS COLOR, OR COLORS.

NOTICE HOW YOU ARE DYING
TO SHOVE IT INTO YOUR MOUTH.

DON'T. SMELL IT INSTEAD.

DID YOU KNOW IT SMELLED LIKE THIS?

OK, PUT IT SLOWLY INTO YOUR MOUTH.

LET IT SIT ON YOUR TONGUE.

DOES THE FLAVOR CHANGE AS IT MELTS?


ARE THERE MORE FLAVORS THAN YOU THOUGHT?


HOLD IT IN YOUR MOUTH AS LONG AS YOU CAN.


DOES THIS FEEL WEIRD?


OK. YOU CAN EAT IT.


GROUNDING TECHNIQUES FOR THE SENSES

5 THINGS YOU CAN SEE 

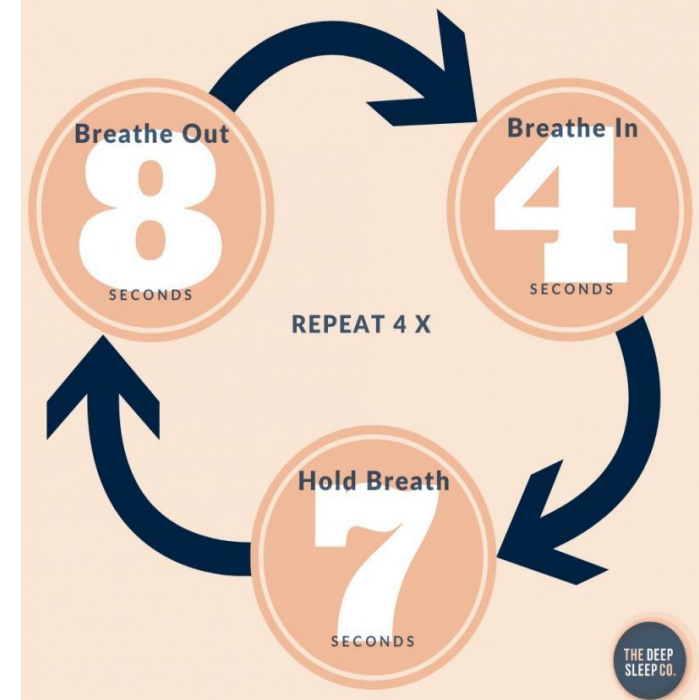
4 THINGS YOU CAN TOUCH 

3 THINGS YOU CAN HEAR 

2 THINGS YOU CAN SMELL 

1 THINGS YOU CAN TASTE 

4-7-8 BREATHING TECHNIQUE



6) ASSESS YOUR ENVIRONMENT

- Establish an environment that is **easy to move around** and work in
- Items regularly used together should be **within reach** AND **stored together**
- Store heavy items at a **low level**
- Keep work areas as **uncluttered** as possible
- Ensure items are in the **same place**



7) MEDICATION



Be aware of changes throughout the day that relate to medication.

Plan your activities around those times



Liaise with a **General Practitioner** or **Pharmacist** regarding **side effects**, particularly fatigue for some medications

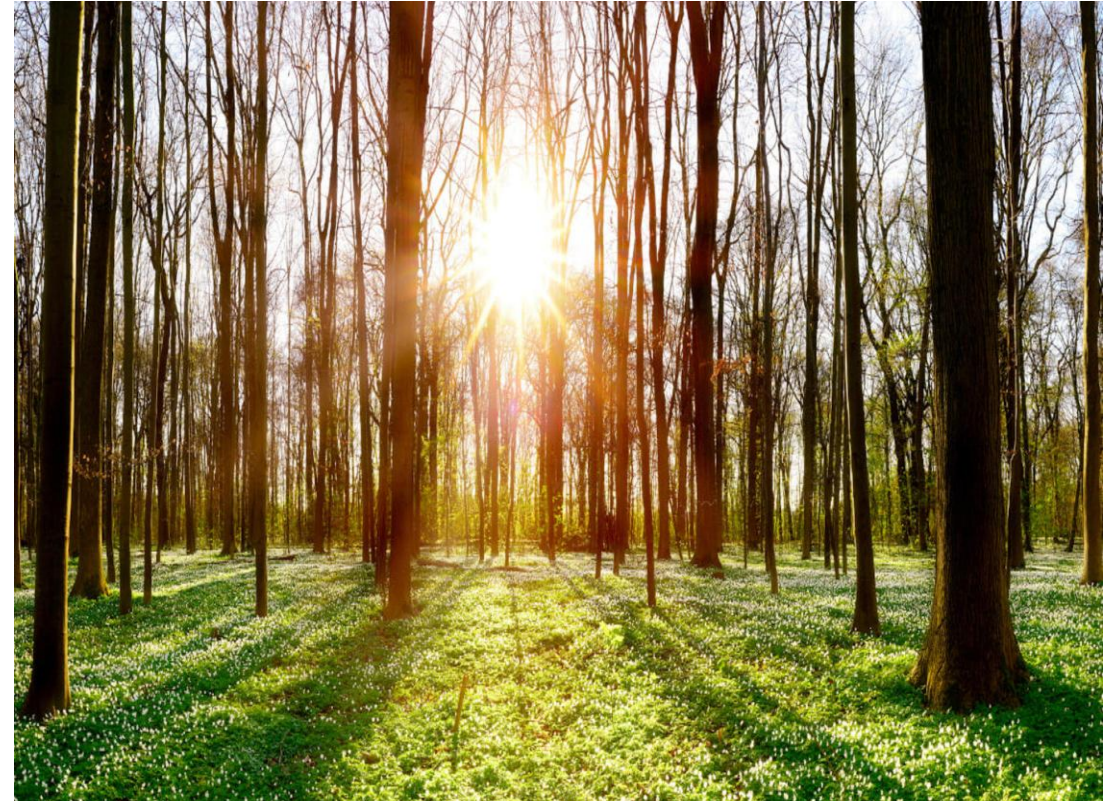
8) HYDRATION



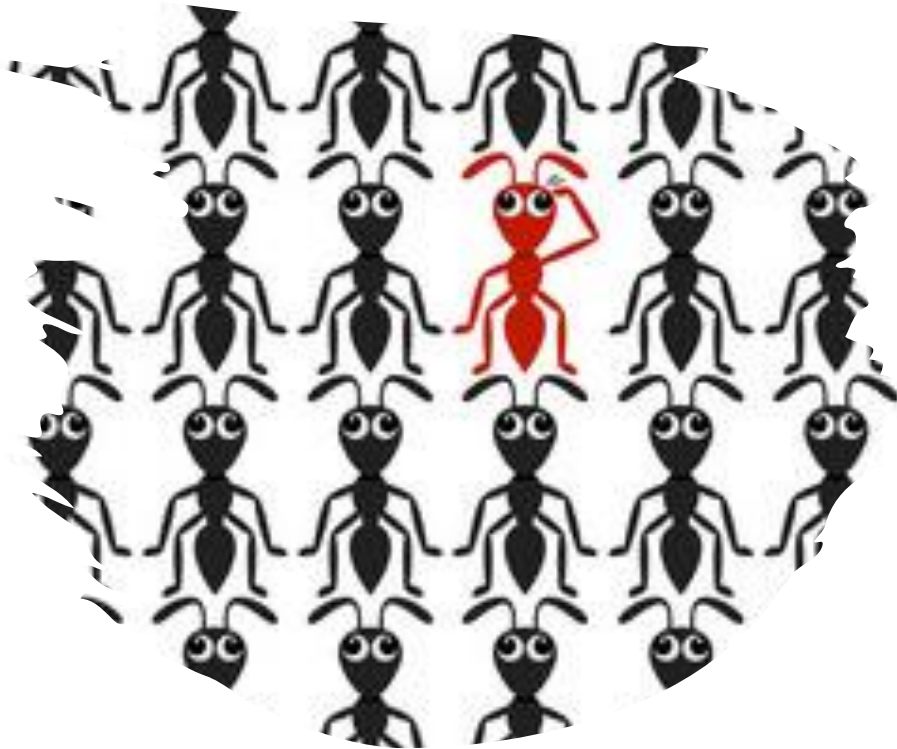
**2%
dehydration
can contribute
to fatigue**

9) EXERCISE

- Try to get **fresh air/nature exposure**
- **Listen to your body** and respect your limits
- **Liaise with a Physiotherapist/Personal Trainer** to devise a personalised exercise programme

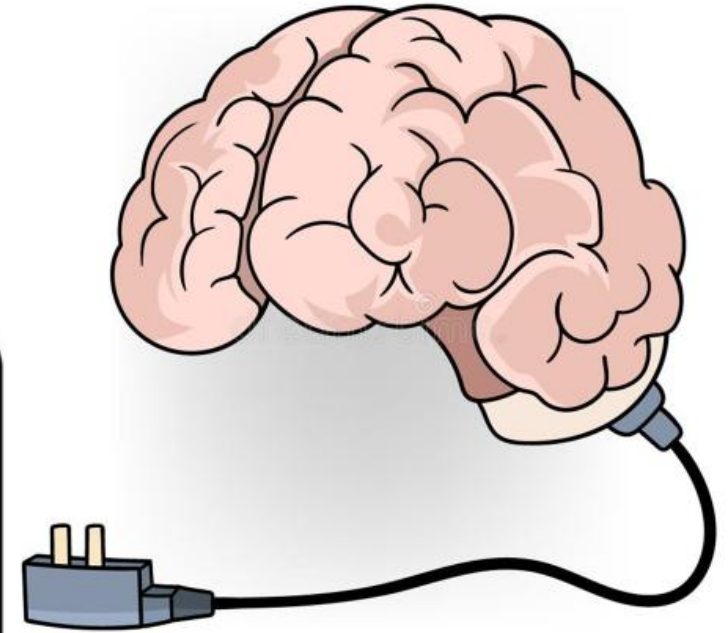


10) ANTs & FATIGUE



- **Automatic Negative Thoughts (ANTs)**
 - Negative words or images that comes to mind
 - Situation specific
 - Conscious and unconscious
- Fatigue can lead to ANTs multiplying
- Thoughts are not facts
- Catch and check the validity of your thoughts – are they fact or are they fiction?

FATIGUE RECHARGE CHECKLIST



Bonus Tip – Targeted Supporters for Fatigue & Wellbeing

- Family / Friends / Colleagues
- General Practitioner
- Pharmacist
- Physiotherapist
- Occupational Therapist
- Dietician
- CBT Therapist



Haemochromatosis, Fatigue, Coping – Final Thoughts

**Managing iron overload is
crucial first**

Fatigue is real consequence

**Be self-compassionate about
your fatigue**

Get to know your fatigue

Seek support



Useful Resources

- Fatigue Dairy Template - <https://www.mariecurie.org.uk/globalassets/media/images/how-we-can-help/living-with-a-terminal-illness/symptoms-and-how-to-manage-them/breathlessness/fatigue-diary-and-planner.pdf>
- Fatigue Questionnaire - <https://www.sralab.org/sites/default/files/2017-06/mfis.pdf>
- Guides on naps, sleep hygiene, and improving restorative rest - [Sleep Advice, Mattress & Product Reviews | Sleep Foundation](#)
- [Homepage - Irish Haemochromatosis Association](#)



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