

SEPTEMBER 2015 . ISSUE . 1

FATIGUE

PID PAMPHLETS

By the people, for the people, of IDFA

DISCLAIMER: The information in this publication is derived from IDFA member experience. The aim is for general information and is not meant to provide specific medical advice.

INTRO

Over the course of 2 months, IDFA members joined in, via phone chat, to discuss their

experiences of FATIGUE. This pamphlet is a compilation of their stories, experiences, management and coping strategies.



Special thanks to members ...

ACT *JENNY TYRRELL*

NSW *CATH BAMPTON, MARGARET JOHNSTON, PAT SUTTON,
CHERYL CULLEN, ABBEY JONES, RACHEL PERRY, KARENNE
BATSON, SHIRLEEN PILTZ, MICHAEL BUCCIARELLI,
MARIANNA KOSITSIN*

VIC *LYN BARKER, NIALL & JACQUI BAIRD*

TAS *NIC SHEARING*

QLD *RELL OLIVER-BRADDOCK, BRIANA CORRY*

SA *NOELENE DAVIES, SHARON HEATHFIELD*

WHAT IS FATIGUE?

Fatigue is a feeling of constant tiredness and weakness which can be physical, mental, or a combination of both. Fatigue can be very debilitating and frustrating. Malaise and fatigue has been associated with PID (IDF Patient and Family Handbook, 2013). IDFA members have described their fatigue in a variety of examples:

ZOMBIE - LIKE (cognitive difficulties)

BRAIN FOG (mental fatigue)

WEIGHED DOWN (physical fatigue)

An understanding of your own fatigue symptoms will help you understand how to manage and cope with your fatigue. Below are some more examples of how members describe their fatigue.

HEAVY

*Battery only
ever half full*

*memory
loss*

*weight on
shoulders*

*Body feels like
it's made of
concrete*

*too tired
to think*

*everything just
slows down*

PID AND FATIGUE

Many IDFA members with PID experience varying levels of fatigue.

“Infections are the hallmark of a PID” (IDF Patient and Family Handbook, 2013) and fighting off infections will cause fatigue. It is always important to keep on top of your regular treatments for PID (e.g. IVIg, SCIg, gamma interferon) to reduce your risk of infection.

IDFA members discussed that...

“Sometimes, with PID, there’s just so much going on in your body it just can’t keep up with it all”

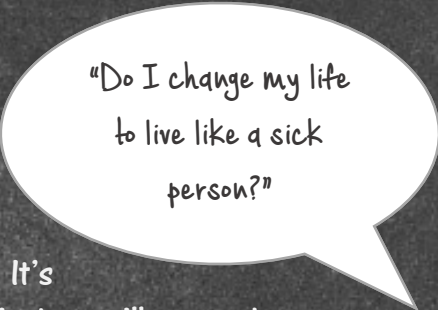


“TIPS & TRICKS”

Management and coping strategies for Fatigue

LIFESTYLE

Finding a balance between everyday life and managing fatigue can be difficult. You may have to make changes in your life. It's important to remember you are more than just your illness and you have a lot to offer this world. Changing your life to manage your fatigue is not giving in to being a 'sick person', its acceptance of what is happening to your body and finding ways to make things easier for yourself!



“Do I change my life to live like a sick person?”

“How much is illness and how much is lifestyle?”

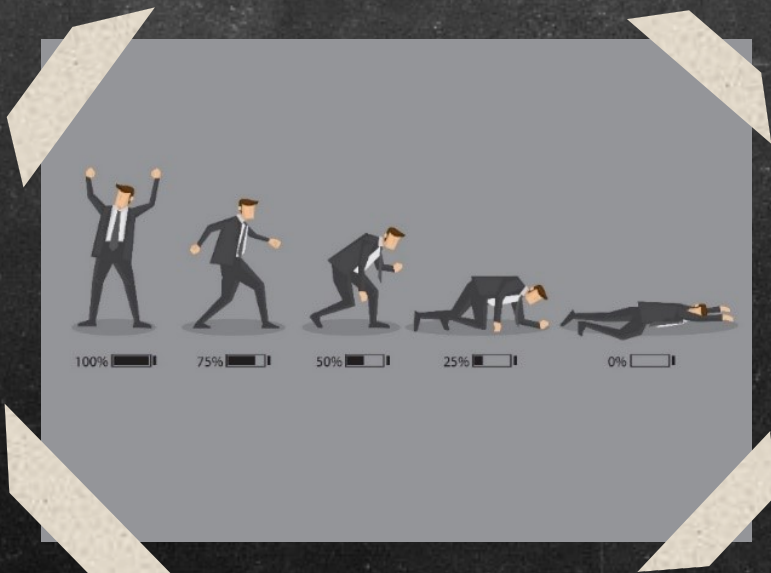
This is where self-management comes in to play. Many people with PID have other health issues as well – such as; allergies, gastrointestinal issues, respiratory problems, migraines, autoimmune illness, and many more! Knowing what's going on in your body is key to separating illness VS lifestyle fatigue symptoms.

THE NEXT FEW PAGES WILL GO INTO DETAIL ABOUT MEMBER IDEAS FOR COPING AND MANAGEMENT OF FATIGUE!

PACING



Pacing yourself is a great way to preserve energy and reduce the risk of burnout from pushing yourself. One member describes pacing perfectly *"Instead of gardening all day without a break and feeling exhausted the next day, I do half an hour, then come back inside and rest for half an hour, then go back out again and repeat."* Pacing can be frustrating at first, especially when you just 'want to get things done' or use the excuse "but I have energy now and I might not have any tomorrow!" - however pushing yourself too hard puts you at risk of crashing down and taking longer to build your energy back up.



RESTING

Resting, together with pacing, is crucial to fatigue management. When you take a break and rest properly, you help recharge your batteries so you can keep going. Planning rest times throughout the day can help with management of fatigue. Resting includes; having a tea break, laying down or sitting in a comfortable position for a time, trying not to think of anything for a few minutes or being too stimulated.

In this busy world, we can feel guilty when resting. It is important to remind yourself that as part of self-management of fatigue, resting will help in the long run. When you go to take your rest break, take a deep breath and remind yourself “it’s OK to rest”.

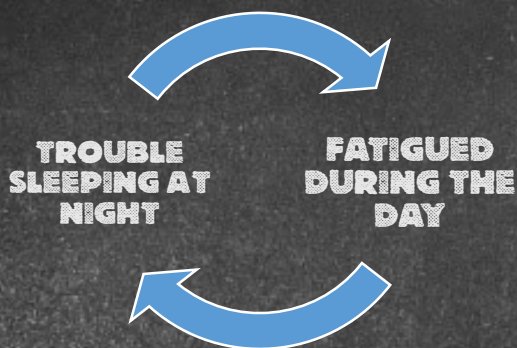
You may need to rest several times a day, planning rest periods is a great way to keep yourself in a routine and help with day to day life activities.

Sometimes, you may be so fatigued you need to sleep in your rest periods – we will discuss this in the following section!



SLEEP

We all know how important sleep is, but getting the mind to turn off at the end of the day and drift merrily off to sleep is often not as easy as it seems. Members discussed frustration at being fatigued throughout the day and having trouble sleeping at night. Of course, this can result in a



horrible cycle of continued fatigue. Practicing good sleeping habits is

known as **SLEEP HYGIENE**. These habits include; getting up at the same time every day, avoiding caffeine and heavy meals before bed time, reducing the amount of naps during the day, and relaxation techniques. Erratic sleep patterns have been shown to have negative effects on the immune system (IDF Patient and Family Handbook, 2013).

It is encouraged to avoid sleeping during the day so you get a better sleep at night time. However, you may be so fatigued that staying awake isn't an option. If this is the case, try limiting your nap to under an hour. Occasionally, if you end up sleeping the whole way through until the next day, don't be unkind to yourself – it could be what your body needs. Of course, if this is happening on a regular basis you should consult with your health care professional.

MEMBERS OWN 'TIPS & TRICKS' FOR GOOD

SLEEP HYGIENE AND IDEAS TO HELP GET TO SLEEP:

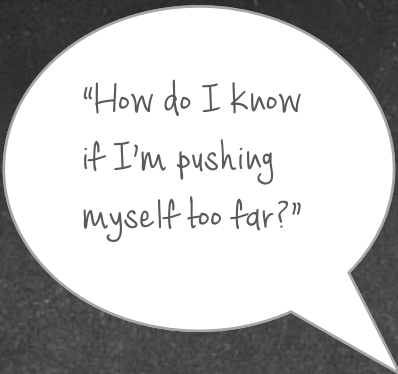
- ◆ *Warm milk (with honey!)* ◆ Have a relaxing bath ◆ Rain App on phone ◆ *soft music* ◆ no caffeine after lunch!
- ◆ **HUMIDIFIERS** ◆ Bedroom is clean and comfortable ◆ *calming tea (like camomile or lavender)* ◆ breathing exercises ◆ heat/colds packs ◆



Sometimes, the longer it takes to get to sleep, the more frustrated you become as you know it will impact your fatigue levels the next day – this frustration will not help, if you can't fall asleep within a reasonable amount of time, get up and start your 'wind down process' again. This could include; reading a book or having a warm drink.

EXERCISE

Some people who are very fatigued have to start as slow as walking 10-30 meters once a day, have a rest day and then gradually increase the distance bit by bit (pacing).



"How do I know if I'm pushing myself too far?"

'TIPS & TRICKS'

IDFA MEMBERS WITH FATIGUE HAVE BENEFITED FROM EXERCISES LIKE:

♦YOGA♦PHYSIOTHERAPY EXERCISES♦SWIMMING♦PILATES

♦Tai Chi♦WALKING♦STRETCHING♦LIGHTWEIGHTS

These exercises are low impact and a great way to start exercising on a low scale if you suffer from fatigue. Some members experience discomfort and a feeling of 'stiffness' when they don't get out there and get moving. It's important to try and get some gentle exercises in your routine 3-4 times a week (a little is better than none, but running a marathon is only for some!).

It is important to note that some kinds of exercise may be inappropriate for people with specific PIDs. For example, a boy with Wiskott-Aldrich Syndrome who has a low platelet count should not engage in contact sports, or people with Chronic Granulomatous Disease should not swim in the ocean or fresh water (IDF Patient and Family Handbook, 2013). Your immunologist can recommend appropriate types of exercise for you if you are unsure.

PAIN:

Some people experience aches and pains, headache, and/or a general feeling of heaviness or being weighed down. Depending on the level of pain, it can be very distressing and, let's face it, a big ol' pain in the butt. What can you do?

IDFA members discuss how to manage pain:

'TIPS & TRICKS'

Heat/Cold packs ♦ Hot shower/bath ♦ physiotherapy/
osteopathy ♦ acupuncture ♦ massage

♦ meditation ♦ HOBBIES (cross-stitch, drawing, knitting,)

♦ listen to music,  ♦ PAINKILLERS (Consult with your gp or
healthcare professional)

HEALTHY EATING

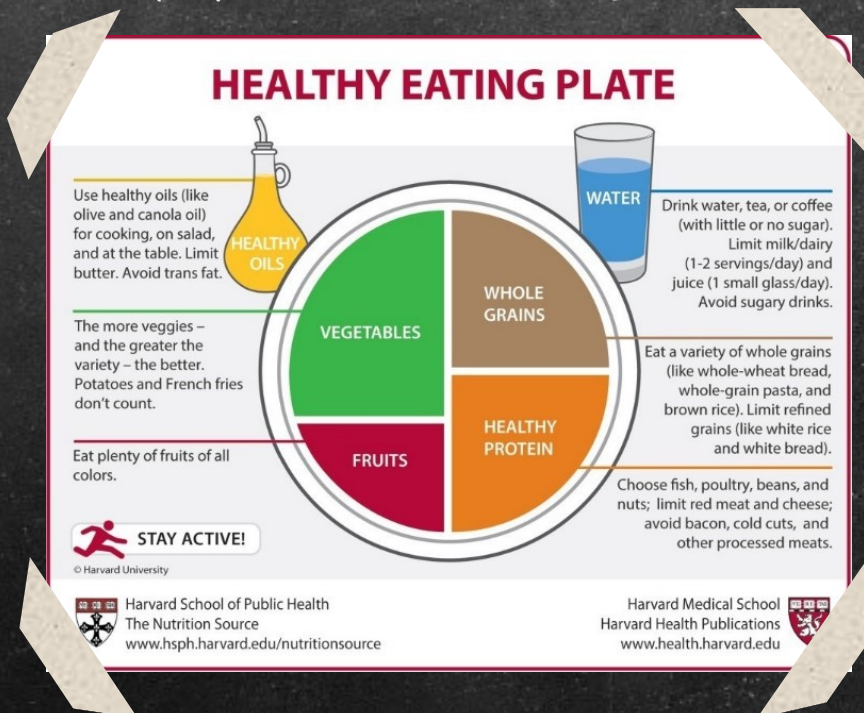
It is important to maintain good dietary habits as part of management of fatigue as lack of nutrition can lead to illness. Some food allergies and intolerances can result in fatigue, check with your health care provider if you think you are experiencing food intolerances. IDFA

members discuss the difficulties in sticking to healthy eating when fatigued and how to overcome these difficulties.

Fatigue issues: Too tired to eat - No energy to prepare healthy meals - Food shopping is exhausting - Food intolerances - Allergies

‘TIPS & TRICKS’

- Keep easy snacks in pantry – like rice crackers and tuna, healthy frozen meals
- Cook meals on ‘good days’ and store in freezer (like soup!) for the ‘not so good’ days
- See if it’s possible to get the groceries delivered
- Ask partner to help out
- Pre-boiled eggs as an easy snack in fridge
- Lite ‘n’ Easy or pre-made, healthier, store bought meals



EMOTIONAL AND SOCIAL

Keeping on top of any emotional or mental stressors in your life can also help with fatigue management. Sometimes, people may experience fatigue as a result of depression, extreme stress, anxiety or other mental illnesses. IDFA members discuss emotional stressors associated with fatigue and tips on how to manage them.

STRESSORS

'TIPS & TRICKS'

STRESS

Self-care

Acceptance

ZOMBIE - LIKE

Write down thoughts in a thought journal

Express self on IDFA Facebook page

BRAIN FOG

Mindfulness

SADNESS

Reach out to support group

Breathing exercises

FRUSTRATION

Meditation & relaxation

Speak to a close friend or family member

ANGER

Have a cry, let it out

Go for a walk to clear mind

Speak to a counsellor or psychologist

STIGMA, FATIGUE AND PID

Sometimes, you may come across people who do not understand what you are going through, they may say hurtful things to you like 'you are just lazy', this is called STIGMA.

WHAT IS STIGMA "Stigma is a mark of disgrace that sets a person apart. When a person is labelled by their illness they are seen as part of a stereotyped group. Negative attitudes create prejudice which leads to negative actions and discrimination."

Stigma Sucks. It really does. IDFA members have discussed the frustration when people do not understand and say hurtful things.

"Other people do not understand"

"I'm tired of being called Lazy"

You are doing the best you can, your energy is precious to you, it is not worth spending it on ignorant people, take a deep breath and let it go. Save that energy for something worthwhile!

Prioritise your energy! Speak to someone who understands, reach out to support groups, have a vent with other IDFA Members.

It can be very difficult when someone close to you does not understand and makes unfair judgements about you. If this is the case, there are a few things you can do: You can use IDFA pamphlets to help you, express that you are hurt by what they have said or how they are behaving, remind them you are doing the best you can under the circumstances.

And remember...

YOU ARE NOT ALONE

IDFA

Immune deficiencies Foundation Australia

www.idfa.org.au

© Chloe Appleton 2015