

Physical and Mental Health

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The Immune Deficiencies Foundation
Australia

Acknowledgement

- I acknowledge the traditional owners of this land, past and present - the **Wiradjuri**

New South Wales Area Health Services Aboriginal Nations Map



NSW HEALTH

Disclaimer: This map indicates only the general location of larger groupings of people, which may include smaller groups such as clans, dialects, or individual languages in a group. The boundaries are not intended to be exact. This map is not suitable for use in native title or other land claims.

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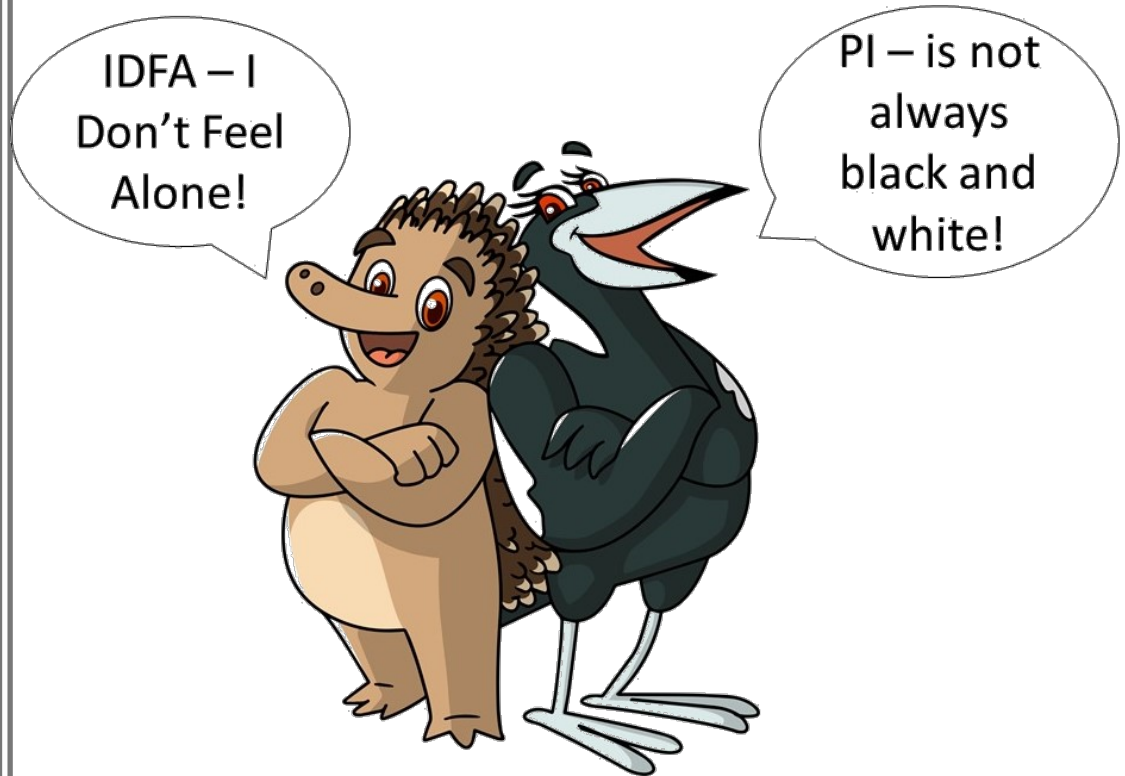
Acknowledgement

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- Chloe Appleton – Support Officer
- Emma Joseph – Health advocacy & communications

About IDFA

IDFA is the peak
patient body
providing support for
people with
Primary & Secondary
Immunodeficiencies
in Australia

www.idfa.org.au



Sid and Maggie.Pi



1:1200
 suspected number of people
 with a genetic
 immunodeficiency that
 significantly impacts their
 health



300
 different types of PI exist



70-90%
 of PI patients remain
 undiagnosed

IDFA is the patient
 organisation raising
 awareness, advocating and
 supporting people affected by
 PI in Australia. Membership is
 free to patients, families &
 Healthcare professionals.

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IDFA
 Immune Deficiencies Foundation
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REQUEST A
 RESOURCE PACK AT
info@idfa.org.au
TODAY

WORLD PI WEEK

10 WARNING SIGNS

- 1 Eight or more ear infections within one year
- 2 Two or more serious sinus infections within one year
- 3 Two or more months on antibiotics with little effect
- 4 Two or more pneumonias within one year
- 5 Failure of an infant to gain weight or grow normally
- 6 Recurrent deep skin or organ abscesses
- 7 Persistent thrush in mouth or elsewhere on skin after age one
- 8 Need for intravenous antibiotics to clear infections
- 9 Two or more deep seated infections such as sepsis, meningitis or cellulitis
- 10 Family history of primary immunodeficiency



Primary Immunodeficiency



q. is there a history
cancer, organ
transplant,
chemotherapy, certain
medications, other
disease (SECONDARY
IMMUNE DEFICIENCY



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**Did the Echidna show
the benefits of early
diagnosis and access to
treatment for those with
secondary immune
deficiency**

**Better
health
outcomes!**



**SYMPTOMS
include:
Frequent,
unusual, or
unresponsive
infections**



**EARLY
testing and
diagnosis is
essential**



**ACCESS to optimal
treatments for patients**



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About Me

- Board member of IDFA.
- sit on various committees in Australia for Immunoglobulin use, Leadership, Immunology, Autoimmunity and the not for profit sector.
 - Board member and Treasurer of IPOPI (International Patient Organisation for Primary Immunodeficiencies).
 - the only Fulltime staff member of IDFA.
- have a background in business and education.

ROLE: Communications, Fundraising, Operations, Finance, Advocacy, Support.

I am passionate about improving quality of life for patients and carers because it's personal!



1990



1999



2004



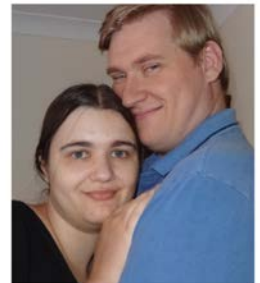
2002



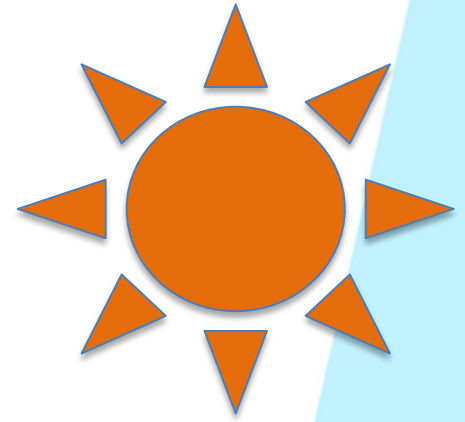
2006



2017



I am a wife, mother,
daughter, grandma, friend,
manager, carer,
and a patient



I like:

1. Albert Einstein's Three Rules of Work.

They are great guidelines for Life.

- ▶ Out of clutter, find simplicity
- ▶ From discord, find harmony
- ▶ In the middle of difficulty lies opportunity

2. To learn a new thing every day

*My goal is for you to learn something new
today!*

Carers

- Carers **provide unpaid care and support** to family members and friends who have a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue or who are frail aged.
- *Carers Australia webpage*
- *As a carer, we often take second place to those we are caring for*

Unpaid work

People aged 15 years and over

	Wagga Wagga (C)	%	New South Wales	%	Australia	%
Did unpaid domestic work (last week)	35,258	71.0	4,127,723	67.7	13,143,914	69.0
Cared for child/children (last two weeks)	14,393	29.0	1,659,250	27.2	5,259,400	27.6
Provided unpaid assistance to a person with a disability (last two weeks)	5,728	11.5	709,415	11.6	2,145,203	11.3
Did voluntary work through an organisation or group (last 12 months)	10,861	21.9	1,103,790	18.1	3,620,726	19.0

In Wagga Wagga (C) (Local Government Areas), of people aged 15 years and over, 71.0% did unpaid domestic work in the week before the Census. During the two weeks before the Census, 29.0% provided care for children and **11.5% assisted family members or others due to a disability, long term illness or problems related to old age ... 2016 CENSUS**

The definition of “Fine”

How are you?

I'M FINE...

Frustrated..

Isolated..

Neglected..

Emootional..



Physical and Mental Health

- Definition of “health”
- Fatigue & management strategies
 - Physical wellness
 - Stress
- Mental health & strategies for coping
- How can health be a more positive concept?
- Cognitive Behavioural Therapy

Definition of Health

The WHO (World Health Organisation) definition of health:

Health is a **state of complete physical, mental and social well-being** and not merely the absence of disease or infirmity.

Being unhealthy is the opposite of being well

PHYSICALLY

- not having good health; showing a lack of good health

- He looked poor and unhealthy.
- unhealthy skin
- His eyeballs were an unhealthy yellow.

LIFESTYLE

- harmful to your health; likely to make you ill/sick

- unhealthy living conditions
- An unhealthy diet/lifestyle



MENTALLY

- not normal and likely to be harmful

synonym unpleasant

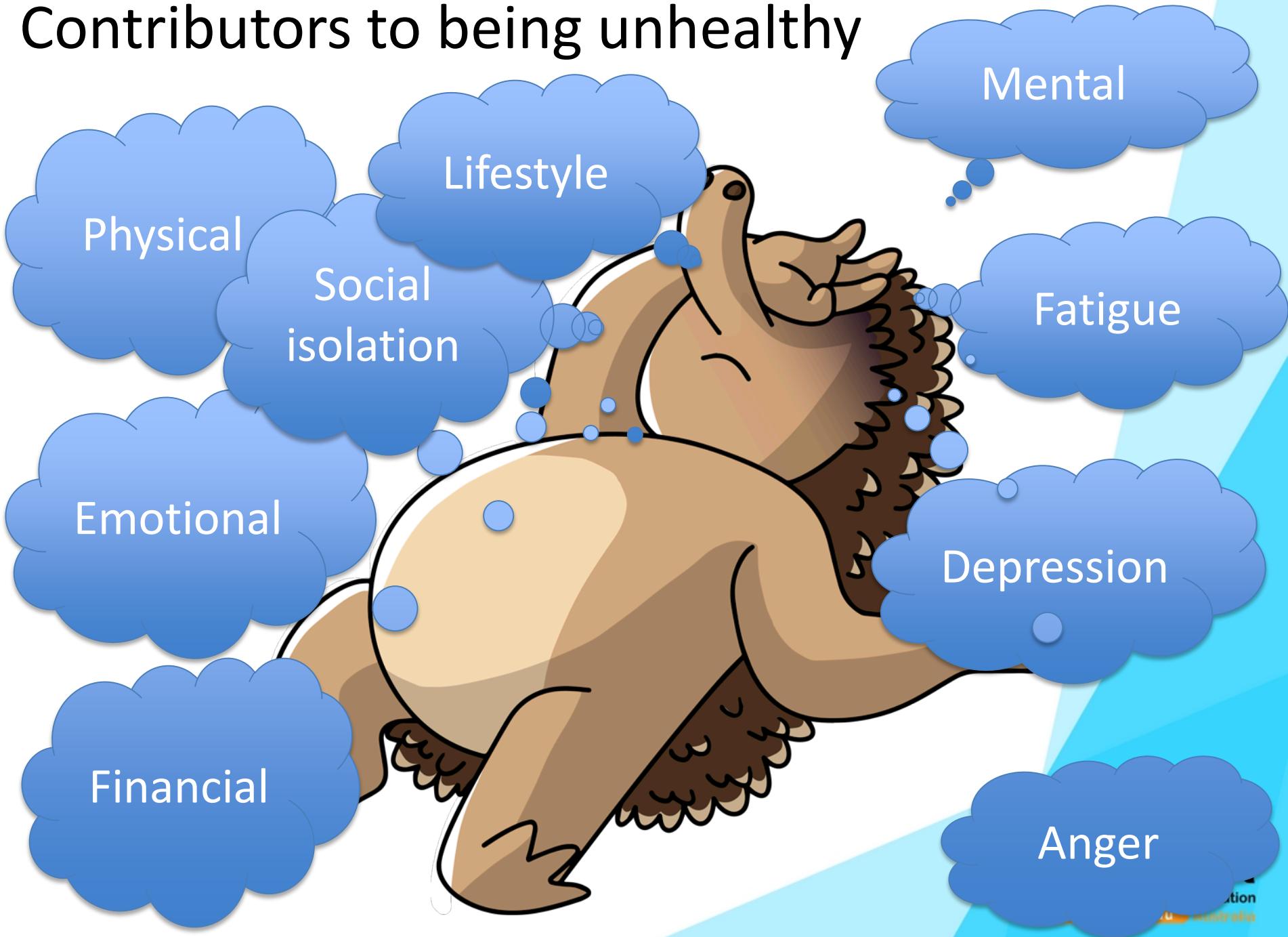
•having trouble with everyday life.

- Disturbing thoughts or actions

Contributors to being unhealthy

What are the
contributors
to being
“unhealthy”?

Contributors to being unhealthy



Back to “I’m Fine”

How are you?

I'M FINE...

Frustrated..

Isolated..

Neglected..

Emootional..



You say you are fine, but are you really???

- Dietrich Bonhoeffer defined health as ‘**the strength to be**’.
- Bonhoeffer says that **health is the ability to pursue our life story without insurmountable obstruction to illness or disability (or circumstance)**.. Unless I am an Olympic skier I can be healthy even after the loss of a leg. I can regain health — I can still flourish — by seeking the courage to rewrite my life script.
- Thus **health can be seen as the ability to flourish without being unduly impeded by illness, disability (or circumstances), AND, by overcoming illness, disability (or circumstances)**..
- *Dietrich Bonhoeffer, (1906–45) German **theologian**. A Lutheran pastor, he opposed the rise of fascism in Germany. Arrested by the Nazis in 1943, he was executed for treason after documents linked him with a failed conspiracy to assassinate **Adolf Hitler** in 1944.*

How is your “health”?

- Are you in a state of “**complete physical, mental and social well-being**” ?
- Do you have “**the strength to be**”?
- Do you have “**the ability to pursue your life story without insurmountable obstruction from your circumstances...**”?
- Are you able “**to flourish without being unduly impeded by your circumstances ...**”?

How many
can truly
answer YES
to these
questions?



Exercise: Think of or write down 3 aspects of your wellbeing you consider unhealthy (can be physical, mental, emotional, lifestyle related)

01

Fatigued

02

Do very little exercise

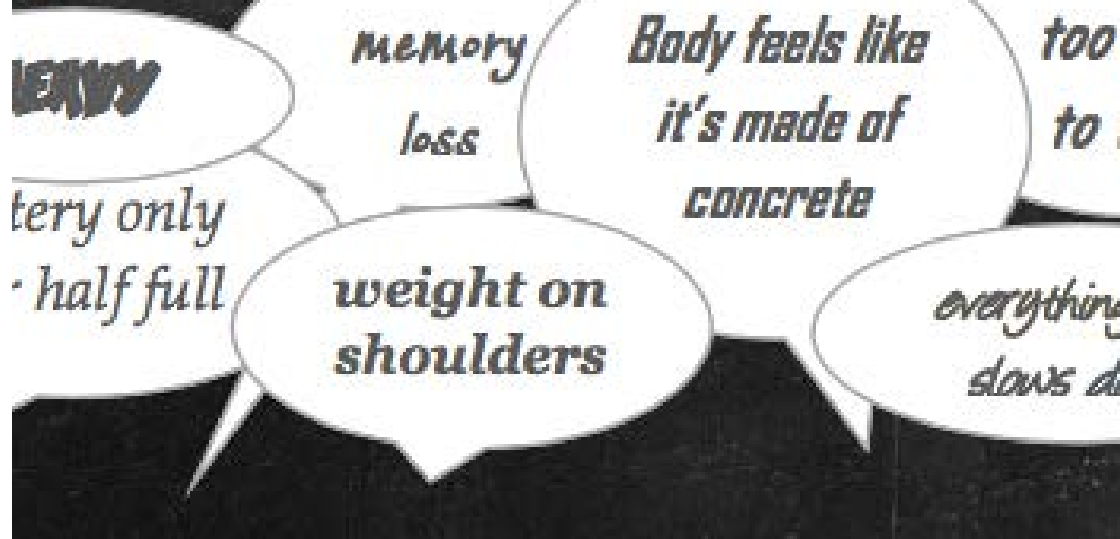
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Stressed

Lets talk
about
fatigue



understanding of your own fatigue symptoms will help
understand how to manage and cope with your fatigue. E
some more examples of how members describe their
igue.



- 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.

What is Fatigue?

Fatigue

- Patients experience fatigue

- IPOD

34

or

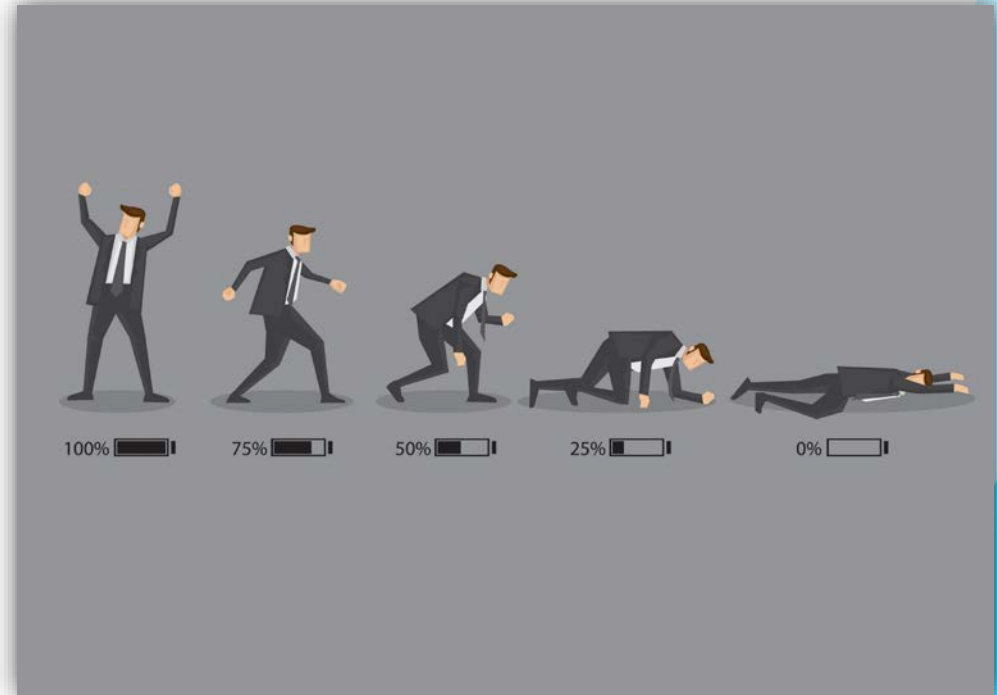
2014

How many of
you feel
fatigued?

MOVING.

Management of Fatigue

- Pacing
- Resting
- Sleeping
- Exercise
- Lifestyle
- Emotional
- Stigma
- Preserving Energy



PACING

Pacing is a key skill to learn in energy management. It involves pacing your exercise and daily activities to avoid “crashing” or “burnout”. It is also a great way to increase strength and general physical function.

- Pacing reduces the risk of burnout
- Can be frustrating, especially when you just want to “get things done”
- Pacing can help reduce the roller coaster ride of fatigue

Resting

Resting, together with pacing, is crucial to fatigue management. When you take a break and rest you help recharge your batteries so you can keep going.

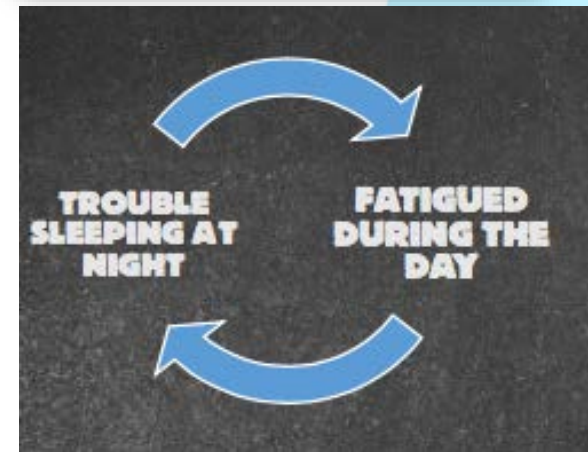
Resting includes; having a tea break, laying down or sitting in a comfortable position for a time, trying not to think of anything for a few minutes or being too stimulated.



- Plan rest and recovery times
- Remind yourself its OK to rest!

Sleep

- Practicing good sleeping habits is known as **SLEEP HYGIENE**
- Not as easy as counting sheep
- Poor sleep means more fatigue
- Avoid daytime naps if possible (I know! also easier said than done)
- Erratic sleep patterns can have negative effects on the immune system *IDFA Patient and Family Handbook, 2013*

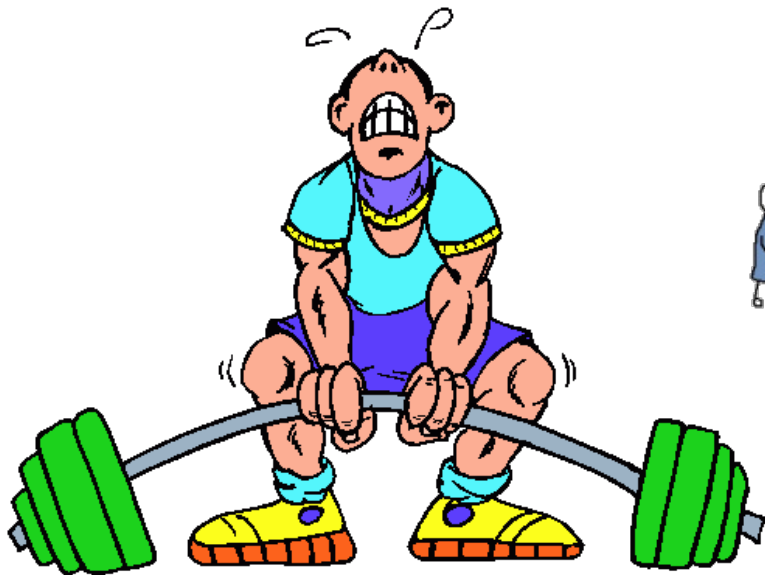


IDFA Member tips

Warm milk (with honey!) Meditation Rain App on phone *soft music* no caffeine after lunch humidifiers Bedroom is clean and comfortable breathing exercises heat/cold pack *calming tea (like chamomile or lavender)* a relaxing bath

Exercise

- Important to know your limits when exercising
- A little is better than none, but running a marathon is only for some!
- Discuss with your GP what exercises are appropriate for you



Healthy Eating

- Too tired to shop for food let alone eat!
- No energy to prepare healthy meals!



Stigma

STIGMA = A mark of **disgrace** associated with a **particular circumstance**, quality, or person.

When a person is labelled, they are seen as part of a stereotyped group. Negative attitudes create prejudice which leads to negative actions and discrimination.

"I'm tired
of being
ignored"



How to overcome stigma

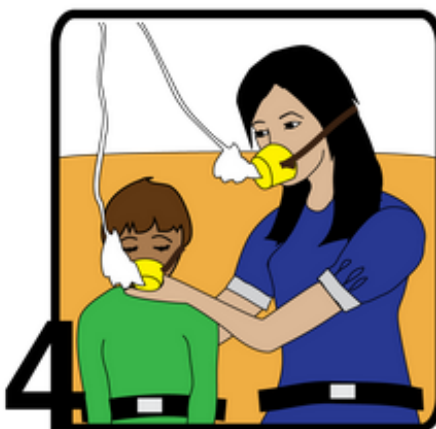
Strangers: be assertive and don't waste energy getting angry

Social Circle & community: Educate, explain what you're going through, provide resources

Preserving your Energy

- Don't use it all at once!
- Know your limits, how much can you spend today, what is most important?
- Don't waste energy on rude peoples comments (instead use that energy for something you enjoy)
- Priorities
- Be smart with your energy
- Learn to say "NO"
- If you burnout, rest and recover

Take care of yourself



- Consider for a moment the advice you are given when you fly on a plane. The flight attendant instructs you to **“put on your own oxygen mask first, before helping others”**. *Self-care is you putting on your oxygen mask first.*

In summary..

- Fatigue is a feeling of **constant tiredness and weakness** which can be **physical, mental, or a combination of both.**
- **FATIGUE MANAGEMENT** includes:
 - Pacing
 - Resting
 - Sleep hygiene
 - Exercise
 - Healthy eating
 - Stigma management
 - Preserving Energy
 - Self care

Let's talk about physical wellness



- Best definition:
- “**Physical wellness** promotes proper care of our bodies for **optimal health** and functioning. There are many elements of **physical** wellness that all must be cared for together. Overall **physical** wellness encourages the balance of **physical** activity, nutrition and mental well-being to keep your body in top condition.”
- <https://shcs.ucdavis.edu/wellness/physical>

Exercise

- Exercise is a vital aspect of self-care and the healing process. Always check with your doctor or specialist.
- The benefits of exercising on a regular basis have positive long term effects compared to exercising 'on a good day'. Tiredness or over whelming feelings may exist, but the movement of the body is a good tip to get through the day.
- Yes, there can be limitations on exercising when you are a carer, however that depends on each individual's circumstance.

What

What do you do for exercise?

- S
- W

-
- Gym
- Resistance

What counts as Exercise?

- Stretching
- Walking
- Yoga/Tai Chi
- Pilates
- Swimming
- Dancing
- Cycling
- Running
- Gym workout
- Resistance bands

BENEFITS OF EXERCISE

What are the benefits of exercise?

- Improves sleep patterns
- Reduces stress and anxiety
- Promotes lung function
- Improves mood
- Allows for teamwork, communication and a feeling of being normal if an individual is struggling with isolation.

SIGNS TO MONITOR WHILE EXERCISING

- Difficulty recovering post workout
- Feeling faint during or after exercising
- Feeling “wired up” and weak at the same time

TIPS WHILE EXERCISING

- Go at your own pace
- Listen to your own body
- Choose low impact exercises
- Include a warm up & cool down
- Limit the frequency
- **Keep hydrated**
- Get adequate rest
- Ensure you are eating healthy to assist with recover and energy



30 minutes of exercise a day

10 + 10 + 10

Break up
your daily
30 minutes
of physical
activity into
10 minute bouts!

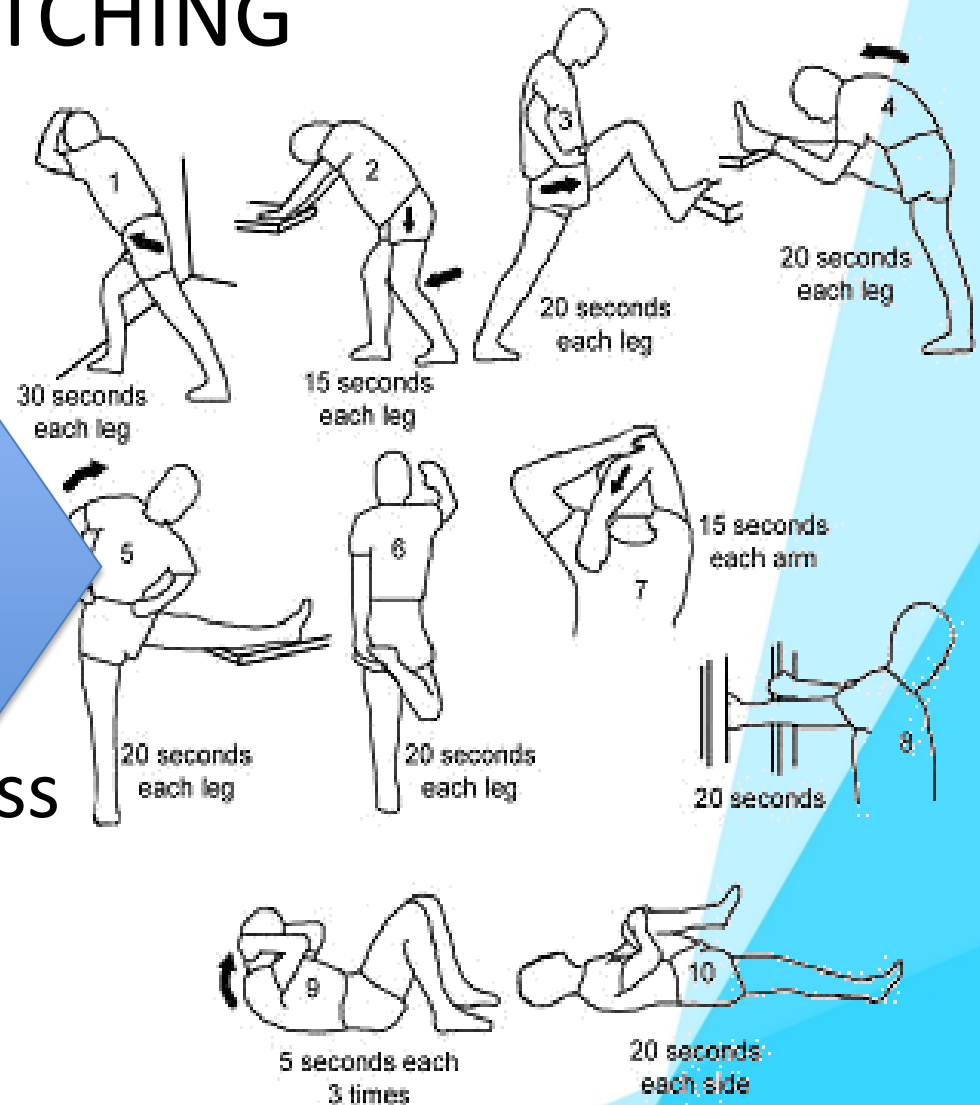
- 2 minutes' walk/jog/dance
- 1 minute jumping jacks
- 2 minutes' walk/jog/dance
- 1 minute each:
 - Squats
 - Push-Ups
 - Scissor Kicks
 - Plank
 - Sit-Ups

Substitute: High Knees, Lunges,
resistance band

STRETCHING

- Relieves str

Don't worry – I
am not going
to make you
do these!!



- Prevents in
- Improves energy levels

Resistance bands

- **Benefits of Using Resistance Bands** for a strength-training routine will:
- Enhance posture
- Increase physical strength and lean muscle mass
- Increase circulation
- Improve balance
- Increase bone strength and health
- Improve your mental health and mood
- Improve your ability to do activities
- Increase your chance of living longer
- Decrease risk of diseases
- Decrease chance of injury
- Talk to your physio for exercises
- Online: <https://greatist.com/fitness/resistance-band-exercises>

