Physical and Mental Health

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Australia
Acknowledgement

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

• This presentation contains information from IDFA’s staff presentations.
• 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

IDFA – I Don’t Feel Alone!

Pl – is not always black and white!

Sid and Maggie Pi
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

REQUEST A RESOURCE PACK AT
info@idfa.org.au

TODAY

Recognise warning signs

Early diagnosis

Better health outcomes!

Optimal treatments

Primary Immunodeficiency
Sid the Echidna shows the benefits of early diagnosis and access to treatment for those with secondary immune deficiency.

**Symptoms**
- Frequent, unusual, or unresponsive infections

**Early testing and diagnosis is essential**

**Better health outcomes!**

**Access to optimal treatments for patients**
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.

I am passionate about improving quality of life for patients and carers because it’s personal!
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
<table>
<thead>
<tr>
<th>Unpaid work</th>
<th>Wagga Wagga (C)</th>
<th>%</th>
<th>New South Wales</th>
<th>%</th>
<th>Australia</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did unpaid domestic work (last week)</td>
<td>35,258</td>
<td>71.0</td>
<td>4,127,723</td>
<td>67.7</td>
<td>13,143,914</td>
<td>69.0</td>
</tr>
<tr>
<td>Cared for child/children (last two weeks)</td>
<td>14,393</td>
<td>29.0</td>
<td>1,659,250</td>
<td>27.2</td>
<td>5,259,400</td>
<td>27.6</td>
</tr>
<tr>
<td>Provided unpaid assistance to a person with a disability (last two weeks)</td>
<td>5,728</td>
<td>11.5</td>
<td>709,415</td>
<td>11.6</td>
<td>2,145,203</td>
<td>11.3</td>
</tr>
<tr>
<td>Did voluntary work through an organisation or group (last 12 months)</td>
<td>10,861</td>
<td>21.9</td>
<td>1,103,790</td>
<td>18.1</td>
<td>3,620,726</td>
<td>19.0</td>
</tr>
</tbody>
</table>

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”
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.

- not having good health; showing a lack of good health
  - He looked poor and unhealthy.
  - unhealthy skin
  - His eyeballs were an unhealthy yellow.

- not normal and likely to be harmful
  - synonym: unwholesome
  - Having trouble with everyday life.
  - Disturbing thoughts or actions

- harmful to your health; likely to make you ill/sick
  - unhealthy living conditions
  - An unhealthy diet/lifestyle
Contributors to being unhealthy

What are the contributors to being “unhealthy”?
Contributors to being unhealthy

- Physical
- Emotional
- Social isolation
- Lifestyle
- Financial
- Depression
- Fatigue
- Mental
- Anger
Back to “I’m Fine”

How are you?

I’m Fine...

Frustrated...

Isolated...

Neglected...

Emotional...
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

03 Stressed
Let's talk about fatigue
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.

Fatigue is a feeling of constant tiredness and weakness which can be physical, mental, or a combination of both. 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.

- Body feels like it's made of concrete.
- Heavy
- Memory loss
- Weight on shoulders
- Everything slows down.
- Battery only half full.
Fatigue

- Patients experience fatigue
- IPOPI's PID Patient Needs & Outlooks Survey 2014
  - 34% of respondents wished for “more energy…not be tired all the time”.
- Carers experience fatigue
  - Physical, emotional, mental,
  - Stress, anxiety and depression can also cause fatigue

How many of you feel fatigued?
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, 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 it's 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.

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

“I’m tired of being ignored”
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 overwhelming 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 counts as Exercise?

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

What do you do for exercise?
What counts as Exercise?

- Stretching
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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 stress
• Increases range of motion
• Prevents Delayed Onset Muscle Soreness (DOMS)
• Prevents injury
• Improves energy levels

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