

Equalities Tutor Time: Chronic Illness and Spoon Theory

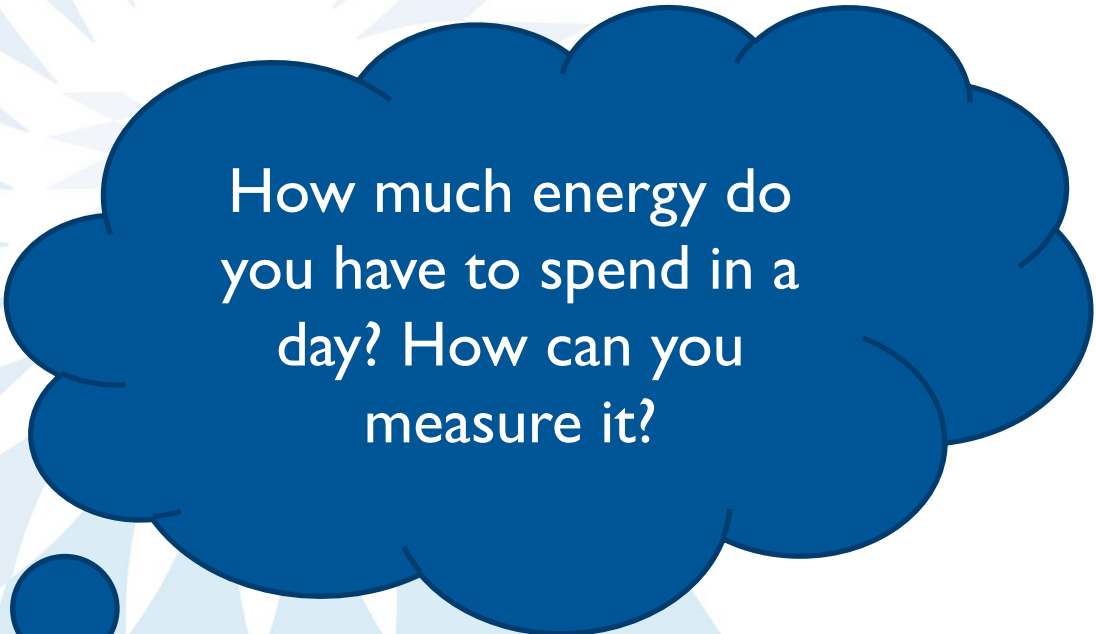
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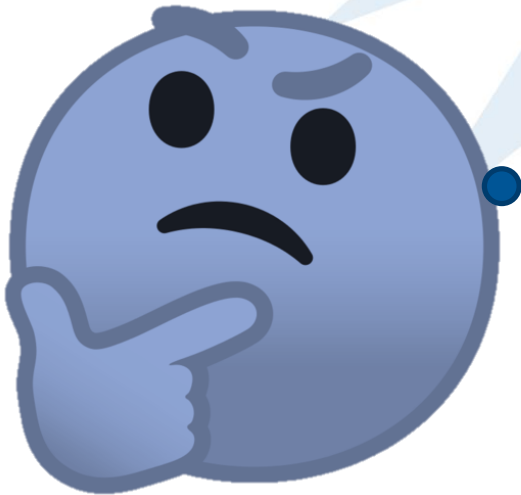
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Education Resource Library

Big think



How much energy do you have to spend in a day? How can you measure it?



Discuss: Does everyone have the same amount of energy to spend? Are there any people who might seem to have less?

Babies/Small
Children

The elderly

Pregnant people

People who are ill

People with
disabilities



A lot of disabilities are what we call ‘invisible disabilities’ – you can’t see someone has a condition, but it is affecting them from inside their body.

If your body is fighting an illness all the time, it takes up a lot of energy, even without moving.

If your body is fighting itself all the time (autoimmune), it takes up a lot of energy, even without moving.

If your body is always harder to control, it takes up a lot of energy just to do basic activities.

If your body is trying to manage pain all the time, it takes up a lot of energy, even without moving.

If your brain is constantly trying to block out information that it finds too much, or trying to refocus, this can take up a lot of energy!

Even sitting trying to work out how to get through the day without making your condition worse can be exhausting!



Spoon Theory is a way of thinking to help able-bodied people understand the challenges of having a condition that takes up a lot of your energy.



<https://youtu.be/VFY81e396ag>

Common conditions where Spoon Theory is helpful to understanding

- **Multiple Sclerosis** (a motor neurone disease)
- **Myalgic Encephalomyelitis** (Chronic Fatigue Syndrome – your mitochondria stop working properly)
- **Lupus** (an autoimmune disease)
- **Fibromyalgia** (a chronic pain condition)
- **Chronic Pain** (caused by historic injury or illness)
- **Leukemia** (and its treatment)
- **Ehlers Danlos Syndrome** (a connective tissue and hypermobility disorder)
- **Mental Health Conditions** (such as depression, anxiety)
- Neurodiversities such as **Autism or ADHD**

This is not an exhaustive list, there are many other conditions where people's energy levels are impacted, including physical disabilities. However, all the ones listed here can be 'invisible', despite the massive impact they have on people's wellbeing.

Imagine that you have a condition that meant you start the day with only 5 spoons. How will you spend them?

Costs 1 Spoon	Costs 2 Spoons	Costs 3 Spoons
Get out of bed	Have a shower/bath	Travel to somewhere outside your home
Brush your teeth	Cook a meal for yourself	Travel home from somewhere else
Eat a meal	Go up or down the stairs	Meet your friends
Go to the toilet	Do some homework	Do your job for an hour
Watch TV for an hour	Do a chore	Go shopping
Scroll on your phone for an hour	Make a phone call	Exercise
Get dressed	Chat online	Go to the doctor
Make a plan for how best to use your spoons	<div data-bbox="691 1011 1889 1130" data-label="Text"> <p>If you overspend today, it comes out of tomorrow's allowance!</p> </div>	


Now remember, tomorrow is likely to look exactly the same. You may have only 4 spoons if you slept badly, or 6 if you are lucky. What will you spend them on tomorrow? If you avoided doing something today because you spent the spoons on something else, how long can you keep avoiding this before you are in a bad situation?

Problems with ‘push-through’ culture

- **In our society, there is a lot of ‘push-through culture’, where if someone is feeling a bit ill, or a bit tired, or a bit overwhelmed, they are encouraged to just ‘push through’ and achieve it anyway.**
 - Lots of people in society are praised and rewarded for ‘pushing through’, for example, mountain climbers and marathon runners – they keep going even when things are tough!
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- **Obviously it is good to have perseverance and not give up at the first hurdle, but if you have a chronic illness or disability, ‘pushing through’ can have a massive negative impact on your health and reduce your daily spoon count for days, weeks or even months.**
 - For this reason, it’s important to listen to your body. Do you need to do more? Will it make you feel better, or worse, in the long run? Telling disabled people to just ‘push through’ is about the least helpful thing in the world.



Think about it... what sort of pressures do you think people with chronic conditions are under?



Pressures from people?

Pressures from themselves?

Pressures from situations and society?

Considering these pressures, how could you show more compassion for people who have less spoons than you?

Invisible conditions with fluctuating symptoms

Importantly, people who have conditions that reduce their 'number of spoons' may well be able to do things like walk, use the stairs, exercise, etc.

However, if this costs valuable spoons, they may end up needing to use wheelchairs, disabled parking or not prioritising exercise to save spoons for more vital things than walking.



not every disability
is visible

People with invisible conditions can be under a lot of pressure to live up to non-disabled standards, just because their disability is not obvious. Remember, just because you don't understand someone's disability, it doesn't mean to get to tell someone how they 'should' be acting to be disabled. You're not an expert in someone else's body!

What not to say to people with chronic illness!



<https://youtu.be/h2J2sj7Rlz8>