

Lifehacks for living with ME/CFS

Presentation for MECFS Canterbury – Slide deck and notes

31st August 2022 by Anna-Maria Covich

Watch the session on <https://youtu.be/JeWUmW0l9J0>



Lorem Ipsum Life Hacks

Tips and tricks for living with ME/CFS
By Anna-Maria Covich

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Note from MECFS Canterbury:

Whether you are newly diagnosed with ME/CFS or have some experience living with ME/CFS, you are likely to find some new ideas for saving energy and managing symptoms from this session. Of course, the severity of your illness and your personal situation will mean some suggestions may not be suitable for you – but they may spark other ideas that help to improve your quality of life.

Find Anna-Maria Covich's blog at www.loremipsumlife.com.

Introductions

Slide 3 - Introductions

Introductions

- Who am I?
- Lorem Ipsum Life
- The tips and lifehacks



Wedding portrait of me, taken by Belinda Lansley. She's an excellent portrait photographer and understands chronic illness.

Who am I?

- My name is Anna-Maria Covich.
- Former microbiology technician, former academic, former university manager, former many things...
- ME since October 2005 following a respiratory infection (corona viridae?)

What is Lorem Ipsum Life?

- My blog about my life with ME. Partly to keep myself entertained, but also to educate people about what it is like living with this illness.
- "Lorem Ipsum Life"
 - place holder text that designers use to fill in plank templates. It looks like content, but when you look closer you realise it's not.
 - I chose it because life with ME can feel a bit like living a place holder of a life.

The tips and tricks and lifehacks.

- friends with post viral fatigue, and potentially ME, after covid.
- I kept repeating myself as I explained to each one how to make life easier.
- I decided I needed to share my tips in a more central place. I wrote about 80 tips, which shared on my blog's facebook page.
- Rose saw these and asked if I could do a talk
- I plan to turn them into a blog post/page at some point too.

Slide 4 – Please keep questions and comments until the end

Please Keep Questions and comments until the end

I've provided handouts and some pens/pencils so you can jot down any questions you have or tips you might want to add.

There are 2 main reasons for this:

If I'm interrupted, I will lose my place and may not be able to pick up again

I may answer the question or cover that idea later in the talk.

- Please keep Questions and comments until the end.
- 2 main reasons as
- my brain is mush, easily side tracked, and prone to losing my train of thought,
- second, I may already plan to cover that later in the talk, and jumping forward will mess with my brain.
- I've tried to make this coherent and logical, but we all know that life with ME isn't either of those things.
- if you don't understand something I've said, ask for clarification.
- I've provided handouts and some pens/pencils (please return these at the end) so you can jot down any questions you have or tips you might want to add.

My core principals of ME management

My core principals of ME
management

Slide 6 – Pinch those pennies

Pinch those pennies

- Never run when you can walk
- Never walk when you can stand
- Never stand when you can sit
- Never sit when you can recline
- Never just recline when you can sleep

- **penny pinch** energy.
 - 5c here, and 10c there, even a few 1c savings, it all adds up quite quickly.
 - give you energy to get through a bigger cost task, pay debt, or live within your means.
- Make it your mantra [read]
- if there's an easier way to do something, do it that way.
- If it can be avoided entirely, then just don't do it.
- I'll give you some examples of what this looks like in practice

Slide 7 – Never run when you can walk

Never run when
you can walk

- You can't be a high powered, jet setting, gym bunnying executive you may have once been or planned to be.
- If you are planning to exercise, keep it LOW ENERGY.
- Never rush.
- Avoid Adrenalin and highly charged emotions or anything else that challenges your body's systems.
- Use a trolley to carry things

- This one should be pretty obvious, and I think all but the newest of our “club” will have learnt this one.
- Slow down your life in every way.
- [read bullet points]
- Use a trolley
 - Instead of walking with a load, walk without a load

Slide 8 – Never walk when you can stand

Never walk
when you can
stand

- Avoid unnecessary walking
- Keep what you need close to where you need to be.
- Ignore convention; arrange your home to suit how you need to use it.
- Redundancy and duplication of the things you need a lot.
- Use a fitness tracker to help keep steps down

- **Avoid unnecessary walking, esp** around the house, including your bedroom.
- **Keep what you need close to where you need to be.** If you need to be in bed, make sure everything you will need is within reach or as close as you can otherwise get it.
 - convention says your kettle belongs in the kitchen, but you only every use it to make a cup of tea that you then take into the lounge, maybe it's better to set up a tea station in the lounge.
 - I have a kettle in the bedroom.
- **Redundancy and duplication**
 - reduces the need to move around.
 - example: A cell phone charger in the lounge and kitchen and bedroom.
 - rubbish bin by the bed and by the door.
 - chair in the hallway.
 - warm throw within arms reach of any chair.
 - **May only save you 5 steps** to put a tissue in the bin, **but add up** those 5 steps and you might save up a trip to the kitchen and back within hours.

Lorem Ipsum Life Hacks for ME/CFS

- expands options for new walls to stare at, and saves some effort if you weren't finished in that part of the house.
- My bedroom has phone chargers in every corner, and there's another in the lounge/dining area.
- There are meant to be throws next to every chair I use too, but a certain 6yo keeps stealing them/
- **Use a pedometer/fitness tracker to help keep steps down.**

Slide 9 – Never stand when you can sit

Never stand
when you can
sit

- Put stools and chairs EVERYWHERE
- Sit to brush things
- Use a perching stool in the kitchen, or use a shallow tub
- Lower is better, sitting in a lower chair or one that lets you raise your feet will help conserve energy.

Why stand if you can sit?

- **Your feet and head are too far apart** and it makes pumping blood hard.
- Standing is hard work.
 - holding all that meat up,
 - brain at top and needs blood that falls to bottom.
 - Brain needs to calculate to keep you upright
 - Anything you can do to assist getting blood to your brain will help your body cope.

- Put stools/chairs EVERYWHERE.
 - A shower stool/chair.
 - If you get dizzy, get one with arms and a back
 - a plastic or metal stool will do the job if sturdy and replaced regularly.
 - A dressing chair/stool in the bathroom and /or bedroom.
 - just to rest between the shower and the clothes,
 - or for sitting and drying off.
 - It lets you sit to put on socks, shoes, and even pants.
 - Sit to brush.
 - Teeth or hair. Use the dressing stool to sit while brushing your teeth,
 - shaving,
 - doing your hair,
 - skincare routine/putting on makeup.
 - You could get a vanity with Hollywood light, but just a stool in the bathroom is plenty.
 - A Bar stool in the kitchen is helpful for doing dishes and cooking, if you don't have or want a perching stool.
 - If a stool is no good, do dishes sitting at a table or on the floor
 - Get a tub, bucket, or bin that can hold water.
 - Fill it using the kettle- cold first, then hot.
 - Don't put too much in
 - To empty it, if you can't lift it/carry it, bail the water out until you can.
 - you can start with a bucket of cold soapy water, put dishes in there to rinse/soak. Then add the hot water then you're ready to wash them.

Slide 10 – Never sit when you can recline

Never sit when
you can recline

- A recliner with a footrest or a foot stool is better than a chair
- Curling up on the floor, or just sitting on the floor
 - Use a big towel or a warm robe and lie down to dry off
- 70s décor is ME friendly
- Recumbent exercises can help with deconditioning (and boredom)
 - see the talk we had on exercise and ME earlier this year

- Recliner with a foot rest - helping your body pump blood.
- Curl up on the floor, or just sitting on the floor (if you can get up and down) is great for conserving even more energy.
- Showering can be so exhausting and you may need to rest as soon as you get out.
 - You could use a big, cozy bath towel on the floor either instead of or over your bath mat.
 - When you get out of the shower, lie on the towel, with another towel over you like a blanket.
 - If you have a warm towelling bath robe, use that.
- Bean Bags are a comfy and cozy way of doing it.
 - Get a larva lamp while you're there and some cozy shagpile or fur rugs to lie on
 - 70s décor is very "in" right now, and very helpful for us. (lol)

Slide 11 – Never recline when you can sleep/avoid activity entirely

Never recline
when you can
sleep/avoid
activity entirely

- You don't need to shower every day.
- Work Smarter, not Harder
 - Burrito roll duvet cover change
 - Ninja fold t-shirts
 - Use a tumble drier with a crease guard setting
 - Hang clothes
- Save your brain. Write it all down.
- Drink through a straw
- Don't sweep the floor if mopping, vac it.

Better yet, avoid it entirely

- You don't need to shower every day.
 - Most people don't really need to shower daily, and doing so can actually be harmful to the skin.
 - 2-3 showers per week is enough.
 - Unless you're sweating a lot, or getting out in the garden etc and actually dirty.
 - If you want to freshen up in between, use a wet cloth to sponge down key areas.
- Work smarter, not harder.
 - Find lower energy ways of doing things.
 - A lot of the later slides will be giving more specific examples of this principal.
 - The burrito roll method for changing a duvet cover is so much easier than any other method I've tried, I can even do it in bed if I have to.
 - You roll the duvet in and out of the cover.

Lorem Ipsum Life Hacks for ME/CFS

- There are lots of videos on youtube.
- If we have time, I can explain it more later.
- Ironing sucks, avoid it.
 - Be naked at all times,
 - wearing all knit or crease resistant fabrics,
 - using a steamer,
 - doing your laundry in a way that minimises ironing.
 - Tumble dry and using an anti-crease setting,
 - or get just the most crease prone items hung up/folded/laying flat ASAP,
 - Not letting them sit in the washing machine for long also helps.
- Write it down.
 - Don't rely in your brain to remember anything.
 - Do try, so it stays nimble, but have it in writing just in case.
 - I have notebooks and I use the notes app on my phone.
 - As much as possible, I like using either an electronic diary or calendar with reminders so I don't forget to remember.
- Drink through a straw.
 - Using a straw means not having to lift the cup. Leave it on the table and sip.
 - There are a lot of options around these days, reusable and disposable: silicone, metal, bamboo, plastic, or paper.
 - The flexi straw was originally invented for bed ridden patients.
 - Travel mugs can be helpful too for insulation and for shakey hands
- To clean your hard floors before mopping, don't sweep, vacuum it.
 - This will lift more dirt and make mopping more effective and far easier.
 - When I worked in a laundry on the weekends, one of my jobs was to clean the floors.
 - Our floors would get filthy, because they were usually only swept during the week.
 - If I swept then mopped, I needed to do 5 passes (3 and 2).
 - When I vacuumed I could do it in just 1 soapy pass and a rinse.

Environment and Lifestyle

Environment and Lifestyle

Slide 13 – Find your limits and your tells – an iterative process



- Learn your "tells".
 - What are the early signs your body gives you that it's reached its limit? There will be many.
 - "way too far" signs easiest because big.
 - find the quiet requests to stop.
 - For me, it's can be how my quadriceps feel. In 2012 I realised my remission was over because my muscles felt different, sort of seized up. When I notice them feeling like that I know I've already done too much activity if I feel that come on.
 - On a quieter level I might notice irritability, headaches, shakes, stomach upsets, burning throat, sore ears, dizziness, brain fog, confusion, jumbled words, aphasia/dysphasia, fluttering heart, facial numbness, a sudden and unexpected spike in blood pressure and/or heart rate, trouble focusing on conversation, nausea... all leading to random uncontrollable tears if I don't stop.

Lorem Ipsum Life Hacks for ME/CFS

- Tells mean STOP as soon as you can.
 - Even just sit down or 2 minutes, or better yet, sit for 15 and have a cup of tea before carrying on. If you can, stop for even longer, call it a night and settle in with an audio book and cuddly throw rug.
- Next Find your baseline.
 - Seriously, this is the best advice I ever read and I have no idea where I read it! I need to do this regularly. Eventually you get the hang of finding it without having to cut back to 4 weeks at 1/2 minimum, but start here.
- Find the minimum level of activity you can **stand to do** in a day.
- Now aim to do **HALF** of that.
- If you find you can manage that without symptoms, move on
- If not, cut back again, aim for half of your previous level.
- When you've found a level where you aren't getting any warnings going off, stay there for 4 weeks, if you can, just to be sure and to reset.
- Next you can carefully add more in, but only add one small increase at a time,
 - the wall will JUMP OUT AT YOU with no warning.
- When you have found that tipping point, stay below that for at least a week.
- At that point, see if you can add a little more each day and recalibrate your tipping point.
- Repeat as needed

Slide 14 – Know where your energy goes

Know where
your energy
goes

- Your energy as a fixed income.
- Emotional energy is energy too.
- Sensory input requires processing effort.
- Limit yourself to 1 thing per day.

- When we're healthy
 - energy is boundless and easily regenerated.
 - For ME/CFS it's like living on the interest from a cash investment.
 - Explain concept
 - Emotional energy is also energy out, even the good stuff.
 - My biggest crash yet came after my wedding.
 - I anticipated it but not the intensity of it.
 - When managing your energy budget, make sure you build stress and positive emotion in.
- Don't over stress your brain with excess sensory stimulus.
 - I find that my brain can't handle a lot of sensory input at once, especially when I'm fatigued, but it's often expressed in weird ways.
 - sunglasses + mask = can't see and just stops trying to understand the images.

Lorem Ipsum Life Hacks for ME/CFS

- listening to something on headphones = can't smell or taste anything (which resulted in burning out the motor on my overlocker).
- Find clothes that are "easy" to wear.
 - Not the same as easy to get on and off
 - items that don't create unnecessary discomfort or awkwardness.
 - Not sitting wrong enough to be uncomfortable, but enough to cause low level awareness of them.
 - This means your brain is constantly doing something (noticing the clothing).
 - eliminate that extra little stimulus, you'll save energy for other things.
 - Example: I have a dress with a big cowl neck and a tie belt, made from an acrylic knit fabric. It's easy to get on, which is nice, but mostly it just sits lightly on my body with no tight bits, nothing too cold or too warm, no itchy bits.
 - By contrast, my jeggings are nice and warm, with a fluffy inner layer that makes me very happy, BUT they're poorly made so they twist and pull down a bit every time I bend or sit.
- Limit yourself to 1 thing per day.
 - This might mean "going out" so you come to the meeting, pick up your grocery order, and stop at the warehouse,
 - or it may mean "going out" to the meeting then immediately back to bed.
 - You may need to average it out over the week, since we can't always shift commitments or schedule our shower day for after that family visit.

Slide 15 – Help a body out

<p>Help a body out</p>	<ul style="list-style-type: none">▪ Identify your ideal temperature range and work with that ▪ Help your Autonomic Systems as much as you can<ul style="list-style-type: none">▪ Stay hydrated▪ Compression clothing▪ Squeeze that butt
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- Find your ideal temperature range and stay in it.
 - I need to be kept warm and can't cope with even the slightest chill.
 - I'm someone from a Jane Austen novel, because I take to my bed quite ill for a week any time I get even slightly too cold.
 - Getting caught in the rain in winter would probably necessitate a heroine sister to abandon her lover in order to sit by my bed for 6 months while she nurses me back to health.
 - I'm also incapable of generating my own heat
 - I need an electric blanket or warm body nearby to warm my feet.
 - I start to feel like it's getting a bit hot when we hit 28-30°C, and tend to feel cold if it's less than 20°C.
- Others with ME need to live in a fridge, overheating around the point where I start shutting down from the cold.
- Find your own range and try to stay within it.
 - Spending too much time too hot or too cold will cause you to crash.
- Stay hydrated. Like seriously hydrated.
- Dehydration will only make everything worse.

- In many cases, extra electrolytes (sodium, potassium, magnesium, and calcium) will be necessary to keep blood volume (and blood pressure) up,
 - but talk to your doctor first about whether this is safe for you as electrolytes can increase blood pressure and can stress the kidneys and heart.
- I aim to drink 3L per day.
 - Most people don't need that much, but I find 2L isn't quite enough to keep my blood volume stable.
 - The rule of thumb for hydration is usually based on toileting.
 - ***You should need to pee every 3 hours, roughly,***
 - ***and it should be straw coloured (champagne not chardonnay is another version I heard) but not clear.***
 - If it's colourless you may be drinking too much and losing too many salts (and blood volume) in your urine.
 - Increase salt if you find you pee it straight out.
- If I'm crashing hard, ***this is where I put all my efforts***, to get my blood volume high so my body can just get on with what it's doing.
- The online talk we had on orthostatic intolerance went into these next tips in a lot of detail – check it out if you didn't see it.
- ***Compression clothing***
 - helps support the blood vessels in the extremities.
 - helps keep your blood pressure more consistent
 - keeps the blood moving.
 - Socks help push lymph back up your body too, rather than pooling in your ankles causing pain.
 - Compression leggings help when walking, or just existing.
- Orthostatic intolerance?
 - The easiest thing to do is curl up on the floor. This isn't always an option,
 - so next best thing is to sit... but if you can't sit where you are (supermarket queues are terrible for this),
 - pump the blood manually by giving your butt muscles a few squeezes.
- You can also help by adopting the "need to pee" posture of crossed legs and slight hunch. Pump your butt muscles from here too for added benefit.
 - I was so pleased to discover that this is actually a thing, because I would sometimes do this instinctively and couldn't work out why.

Slide 16 – Make resting your day job

Make resting
your day job

- Treat resting like its your full-time, work from home job and set yourself up accordingly.
- Make your bed somewhere nice to be
- Make yourself an office/motel suite, with ensuite
- Have a second “oasis of calm” if you can.

- Treat resting like its your full-time, work from home job and set yourself up accordingly.
 - fit for purpose work space, right?
 - Make your bed somewhere nice to be.
 - Nice sheets,
 - comfortable mattress,
 - blankets of the right weigh for you,
 - good pillows,
 - a cuddly teddy bear for company.
 - These will help you rest and feel good while you're there.
- This one has helped me immensely, but I totally recognise it's not an option for everyone.
- Model your bedroom on a motel room.

Lorem Ipsum Life Hacks for ME/CFS

- Bathroom,
- mini fridge and kettle,
- basic food prep facilities all within a few steps of your bed,
- with somewhere to sit too, if you can.
- I have a mini fridge with milk, yoghurt, and the other half of my can of peaches from breakfast.
- I also have a kettle, espresso machine (morning coffees in my personal cafe), cutlery, bowls, cups, cereal, snack foods etc.
- I use my ensuite sink to wash the dishes, but I could use a small tub or bucket on a tea trolley to dump them/soak them and take them to the kitchen if I didn't have that resource.
- Have an ensuite. If you have a bedroom with an ensuite, yay!
 - If not, and you have options of bedrooms or bed locations,
 - put your bed as close to the toilet and/or bathroom as you can.
 - It may only save you a few steps, but those steps might be half of your daily activity some days.
 - When we were looking for a new place to live last year, and ensuite for me was one of our key requirements. There were houses where "my bathroom" would have been on the other side of the lounge, or upstairs. I almost applied for some very inappropriate ones, but my flatmate and husband pointed out that no, I could not "make that work".
- build yourself an oasis of calm that isn't your bed.
 - Find a nice chair and put it somewhere with a nice view.
 - The view may just be your spider plant collection, a nice picture, or some fairy lights, as long as looking at it makes you feel good.
- Add a rug, a cuddly blanket and plop yourself there for a change of scenery and posture.
 - It will do your body and mind a lot of good to stare at a different set of walls,
 - or the same walls from another angle,
 - or out a window.
 - If you can get out of bed and move somewhere else every day, even if it's just a different bed where you can watch tv, you will find it easier to sleep at night when you do go back to your sleeping bed
 - I have an armchair in my room with a nice poof footrest that I made. I sit here, wrapped in a blanket, legs over the arms reading a book or listening to an audio book or just soaking up late afternoon sunlight. I often fall asleep in it.

Lorem Ipsum Life Hacks for ME/CFS

- I have a less comfortable chair, more of a reception chair, on the porch.
- I've added trellis, a rug, curtains, and pretty lights to make it serene.
- I have a throw out there for summer nights, but in winter I can take a warm blanket and watch my patio garden of potted veges grow (aka. Slowly die. I'm not very good at plants) and enjoy some fresh air. Sometimes I read a book in the sun.
- If you can leave the house, you could try what I call "day camping"
 - It's like an extended picnic.
 - Find a nice spot where you can go and just be there all day.
 - Take food, a thermos, extra blankets and cushions to be comfy.
 - Think Downton Abbey's version of a picnic.

Slide 17 – Invest where you rest

Invest where
you rest

- Get some plants
- Antigravity loungers
- Pillows, all of them
- Sleepwear
- Over bed tables

- **Invest where you rest.** If you're going to spend money, spend it on making your rest area nice.
- Get some easy care pot plants for the bedroom.
 - If the room gets stuffy; plants are nice to look at and help keep the air fresh.
 - A snake plant, peace lily, or spider plant are excellent at keeping your air fresh and oxygenated with very little care or light needed.
 - ferns if you can water them
 - Luck bamboo is good in low light but can take a little more care.
- **Anti gravity loungers.**
 - There's a style of chair and bed available these days that is so much more relaxing than anything else I've ever used it amazes me.
 - It has you lying in a horizontal zig zag, feet about level with the head, hips slightly lower, knees slightly higher.

- I bought a deck chair version a couple of years ago and absolutely love it. My whole body lets go when I recline in it fully.
- **Pillows.**
 - all of the pillows.
 - And some cushions.
 - Wedges, bolsters, euro, standard... all of them.
 - You might only sleep with 1, but during the day, having a huge pile of pillows available lets you **build a fort...** base for comfortable sitting.
 - Put a bunch behind you, support your head and neck too, put some under your knees, legs, and feet, support your book etc.
 - Mould them into a nest that keeps you in the perfect sitting position.
 - You can even use them as a makeshift futon if you want to move the party to the floor.
- **Nice pyjamas, lounge wear, and/or a bed jacket.**
 - These are now your 'work clothes' so get nice ones.
 - Nice pyjamas are nice for lounging and sleeping.
 - A bed jacket is an old fashioned garment but so worthwhile if you spend a lot of time in bed.
 - it's a short cape or jacket made from a similar fabric to a dressing gown
 - wear over your shoulders to keep you warm (and modest) when sitting up in bed.
 - It's just long enough to be cosy but not so long it gets in the way.
- **Over bed tables.**
 - The kind they use in hospitals that has a foot that rolls under the bed and a tray that slides over it, preferably with a tilting section.
 - If you can't get one of these, a bed tray, the kind with legs for serving breakfast in bed, will do.
 - These are great for eating, artsing and crafting, playing cards, doing a puzzle, or even just to have your drink, meds, and a book close at hand for napping and waking.

Better living through Technology

Better living through Technology

Slide 19 – Mobility aids

Mobility Aides and other useful gadgets

- Balancing takes a lot of energy
 - Walking sticks
 - Walls and other solid objects
 - Fixed point in your vision
 - Walker, with a seat
- Online shopping for buying and purchase browsing
- Fully adjustable ironing board
- Reading glasses
- Thermos flasks and travel mugs
- Running belts
- Audio books
- Don't limit things to what the designers thought it was for

- **Mobility aids.**
- As mentioned, Balancing takes a lot of mental energy.
 - A walking stick can help your brain save energy by giving you a physical point of reference for space, gravity, surface angle etc.
 - Don't lean on it unless you're unstable, just use it like you would a hand rail on an escalator, to stabilise yourself and keep you centred in space.
 - It's just there as a third point of contact.
 - If I don't have my stick (or walker) I find I fatigue really fast.
 - I try to use something else as my point of reference, such as touching the wall, or lamp posts as I pass, or holding my husband's hand.
 - Alone in an open space I use a technique that dancers and yogis use to balance when on one leg.
 - Pick a fixed point ahead of you and focus on it.
 - It needs to be something reasonably close and still.
 - It could be a point on the ground up ahead or the door handle across the room etc.
 - try not to take your eyes off it as you walk.
 - If you need to look around, try to pause, look, then look back to your spot as you start again (unless that's unsafe. Use your judgement).
 - Giving your brain some solid, 'I'm moving, but that isn't' cues to help it keep track of your position and orientation will save it a really surprising amount of energy.
- Get a walker with a seat.
 - I can put my handbag/shopping/drink bottle in the basket or on the tray, and use both hands on the handle, which means my brain does almost no work for balance and spacial processing.
- Online shopping is one of the best inventions of the 21st century.
 - Online grocery shopping is amazing.
 - I use click and collect, because I'm ok with that level of activity.
- Even if you don't want to actually purchase the item online, online shopping lets you
 - research what is out there
 - and potentially even find which stores have it in stock, making for a far more efficient trip when you do make it in.
- Get a good ironing board. But look carefully.

- I'm generally against ironing clothes, but here's where an ironing board can help.
- An ironing board with a fully adjustable floor to tall person range can be used as a dining height table on front of an armchair, at coffee table height, or you can iron clothes from the comfort of a chair if you really must iron things.
- get some reading glasses.
 - walking stick for your eyes.
 - Also, use as much light as you can stand when reading. I know it can be balancing act, but your eyes need light to read.
- **try using thermos flasks.** If you can't have a bedroom like set up like mine, but still really want to have hot water in bed for a cuppa or a hot water bottle
 - 2 smaller ones will be better than 1 big one, because you can lift them easier and you don't lose as much heat from your water every time you pour a little
- **Running belts. This is mostly for pocketless ladies...**
 - It's just a tube of stretch material in a loop with some splits in the top to create one long, circular pocket.
 - When I leave the house I like to have my phone, my keys, often my wallet (my main cards are in my phone case), a drink bottle, a walking stick, but I don't necessarily want a handbag.
 - The running belt fits close to my body, so it doesn't bounce around and upset my centre of gravity, nor does it give me a giant lump on one side of my body.
 - I can't fit my water bottle in the belt, and I use the stick when walking, so if I put everything else in the belt, I have 1 hand free for my bottle (if I'm using it), and the other for my stick.
- **Audio books and podcasts** are a really easy to use form of entertainment.
 - Close your eyes, stay in bed, and listen.
 - Most libraries have an audio book and ebook reading apps so you can get them for free without even having to leave your bed.
 - I particularly like books that have been dramatized, or ones where the reader gives each character their own voices.
 - It helps me follow conversations and keep track of who is where (I sometimes struggle with this in real life, even with voices and visual cues)
 - You can slow down the recording if your brain needs longer to process language.

Lorem Ipsum Life Hacks for ME/CFS

- You can bookmark where you started each session, so if you fall asleep or just drift you can find your place again.
- Most apps also let you set a sleep timer so it will stop at the end of the chapter or after a set time.
- Librivox is another free audio book option. It's all public domain books (i.e. mostly older) read by volunteers.
 - They usually have different people reading each chapter (with a handful of volunteers doing each book), and some are dramatic readings.
 - The quality varies, but there's a huge selection of classics.
- **Ignore what things were designed for:**
 - Slice cucumbers with the long flat cheese blade side of a grater.
 - If you don't have a cheese slicer, you can use a potato peeler to thinly slice cheese.
 - You can also use a peeler, grater, or cheese slicer to shave butter off a cold block to spread on toast.

Slide 20 – Kitchen and Laundry

Kitchen and
Laundry

- Kitchen tools
 - Food processor
 - Pull/USB blender
 - Microwave
 - Dishwasher
 - Mandolin chopper
 - Kettle cradle
 - Oven timer
- Laundromats
- Laundry trolley
- Drying racks
- Sturdy box and scoop for powder or dispenser for liquid

- **kitchen gadgets can save a lot of energy**
- **There are some obvious ones...**
 - I have a **small manual chopper**.
 - It's like a tiny food processor that you operate by pulling a string.
 - It's small and light and easy to clean, so good for small jobs
 - Tupperware did one with a handle on top that you turn.
 - They're geared, so just a few pulls or turns will totally mince an onion or some garlic.
 - You can get electric versions too that are rechargeable via usb.
 - The hand blender is great for onions and garlic, and making small batches of things like chocolate hummus.
- If lifting the kettle is too hard or unsafe for you, there are these **cradle devices that hold and pour the kettle for you**.
- If your brain fog makes cooking hazardous, **set the timer on your oven**.

- Most ovens these days can be set to turn off and buzz an alarm after a set time.
- **Vented driers and laundromats** aren't as expensive as you'd think.
 - My current house doesn't really have anywhere that we can put our tumble drier, so we go to a laundromat.
 - The large commercial driers are super-fast and can hold masses of laundry.
 - Last year we generally spent about \$10-15 per week on drying our laundry (about 3 loads of towels, 2-3 of clothes and maybe a small load of bed linens).
 - We'd do it all at once, go there for 40 minutes, use 2 or 3 driers and get it over quickly.
 - Some laundromats even have a service option, which is often not much more than DIY,
 - and some even do pickup and delivery services.
- If you want to hang your washing on the line to dry but it's too hard to bend and lift. I have 2 ideas here.
 - **A laundry trolley** might work for you.
 - They are basically an X with wheels and you sit a basket in it.
 - You unload the machine, push this to the line and start hanging stuff.
 - The basket is elevated so don't have to bend, just stretch,
 - don't carry the basket of wet washing either.
- Drying indoors dampens the home, so doesn't save much, if any, power compared to a vented tumble drier, once you factor in heating the added dampness.
 - **BUT put the rack outside** (under your clothesline is a good spot)
 - hang clothes outside but without bending and reaching up.
 - You can get drying racks with a continuous line from one end to the other and a moveable support strut so they're long enough for hanging sheets.
 - I put all shirts, T-shirts, dresses etc that can go on a hanger on hangers to maximise the space on my rack and minimise ironing.
 - There are also racks with an extra rail above.
 - A height adjustable mobile clothing rack is also good for this.
 - A sturdy box and scoop for powder or drinks dispenser for liquids
 - Minimise how much you have to lift

Slide 21 – We're living the future, after all

We're living in
the future, after
all

- Electric tooth brushes and water picks
- Remote control and automate your house your house:
 - Wifi, timer controlled, and motion sensor light bulbs
 - Wifi and app controlled power boards
 - Wifi and app controlled heaters
- Robot servants

- **Electric toothbrushes.**
 - You can get a lot more brushing done with an electric brush before you get tired than you can with a manual brush.
 - Even if you have to sit with your elbow on the bench for 2 minutes, that's pretty low effort.
 - If you can't handle 2 minutes, 30 seconds with an electric brush is better than 3 seconds manual brushing and takes less effort
- **Dysautonomia**, which comes with the territory, can mean our bodies stop taking care of our teeth. That means we have to work extra hard to keep our teeth healthy.
- **Wi-Fi lights and power boards.**
 - I don't have these, but my dad does.
 - His lights have **motion detectors** and turn in when you enter a space,

- They even send him a message to say someone is in the house if he's away and I happen to pop in (usually to water his plants).
- That's not helpful for ME/CFS but it's still neat.
- **Wi-Fi lights** can have all sorts of **automatic profiles** set,
 - turn on brighter or dimmer at certain times,
 - automatically turn on it off at certain times,
 - turn on dimmed and slowly brighten,
 - have certain colour temperatures at different times,
 - all depending on the set up and bulbs you get.
 - These could all be of use in different ways, but the biggest use I think I'd get out of them is being able to turn them on and off or dim them without having to move.
- This can extend to **other appliances too**,
 - like heaters, if you use a wifi/app power board.
 - Some heaters have on board app control.
- **Robotic vacuum cleaners** are excellent.
 - They're best if you run them daily as they don't pick up as much as a manual jobby,
 - Most can be set to run on a timer.
 - Some can be driven by remote via a phone app.
 - More fancy ones have a tank and mop attachment and can be set up to mop the kitchen floor when they've finished vacuuming.
 - My flatmate bought one for the common areas, and its doing a pretty good job of making it look like we actually tidy up. I want to get one with a mop and tank for my room, since it's huge and has wooden floors.

Food tips

Food tips

Slide 23 – The easiest food are done for you

The easiest food
are done for you

- The usually rules don't apply to us*
- Fruit bowl in the bedroom
- Premade salad bags
- Premade soup and risotto pouches
- Microwave ready meals
- Breakfast bickies and boxed smoothies

*most of us

- Do you know why nutritionists don't like ready meals and convenience foods?
 - **Most are really high in salt.**
 - Do you know what the one dietary recommendation is given to most* people with ME/CFS?

- **Eat a high salt** (an extra 5g per day, usually) and high water diet (salt disclaimer).
- So, go and eat ready meals and convenience foods!
- Canned stews, frozen dinners, stir through sauces.
- Knock yourself out.
- Just make sure you drink water too,
- and get enough potassium on the side.
- Watch the added sugar content on these though as some can be quite high.
- What we do need to focus on is getting enough **fibre and fluids**, since we're rather more sedentary than most, which is not great for the bowels.
 - Put a **fruit bowl in the bedroom**.
 - Even if you can't have a full motel room set up, like I have, a fruit bowl will be helpful.
 - Load it with any fresh fruit you can eat.
 - Fruit is a no prep snack that gives you fibre and lots of good nutrients.
- **Pre-made salads** can be amazing value, depending on what you get.
 - Prepared prepacked salads and veges can also make adding veges to a meal much easier.
 - Don't wash, peel, slice, grate and mash, just open a bag and dump a handful of the contents on your plate.
 - I've found a few that even have protein in them (Taylor Farms chopped Caesar with chicken, and chicken avocado slaw are both excellent)
- **Soup is awesome.**
 - pre-made healthy soups, stews and risottos from the deli fridges at the supermarket.
 - open the bag, heat the soup, serve and consume.
 - These soups are usually packed with veges and good protein, so are very nutritious.
 - They last for ages, so you can stack a bunch in your fridge each week, or even freeze them if you want to get them in bulk.
 - Instant cup-a-soups and miso are a great option if you want a filling, low effort snack
 - be aware that powdered soups are high in sodium (up to 1/4 RDI per serve).
 - If you need that extra t-spoon of salt each day this is a great way to get it,

- **Convenience foods** have come a long way in the last few years.
 - You can buy all sorts of fantastic meals and meal components in pouches and long life pots that can be stored in a cupboard and microwaved (or heated on the stove, in most cases, so they're also good for emergency kits).
 - More expensive than making the meal yourself, but cheaper than takeaways, compromise between effort and money, as most things are.
 - There are ready to eat **pasta meals**, and **almost instant fresh pasta** from the deli fridge is a great option - just boil some water and cook them for 2-7 minutes, depending on brand and type. I add a little butter or stir through some pesto and we're done.
 - There are **microwave pouches** of rice, risotto, soup, rice and quinoa, curries, stews, noodle pots... So many options.
 - There are some really good pouch and box meals around, like the “plant based” line from Watties, iirc.
 - The deli fridge usually has heat and eat “takeaway boxes” of Indian or Thai curry or Chinese etc.
 - Some supermarkets package up single serve roast meals too
- Breakfast bickies/boxed smoothies
 - Belvita make these fantastic bickies that are designed to replace a bowl of cereal for breakfast on the go.
 - They have lots of fibre, not too much sugar for a biscuit, and come in wee sealed portions.
 - They're not a nutritionally complete meal, but they are an excellent option for breakfast or lunch if you can't get up and about right now.
 - OSM bars are very filling, and designed to be one square meal of food.
 - Up and go, or other similar smoothie products are a good option too.
 - They are UHT packed, so don't need to be stored in a fridge and are a good source of protein, fibre, and fluids.

Slide 24 – Next best thing is anything easy

Next best thing
is anything easy

- Home made (or purchased) instant porridge (recipe)
- Not stirred or fried microwave stirfry
- Chocolate hummus (recipe)
- Frozen fish parcels (recipe)
- Slow cooker
- Boiled eggs
- Falafel bites

- One of my favourite breakfasts
 - instant porridge, the type you mix in a bowl with boiling water, or nuke with cold water.
 - I like this because I can make it in bed.
 - But I'm also poor, because I can't work, so buying sachets of the ready to go stuff is out of my budget.
 - I make my own instant porridge.
 - I've included my recipe in the handout
 - I'll usually make a big batch and fill a couple of 2L jars once every few weeks.
- Another recipe – a stir fry which is neither stirred nor fried.
 - This was one of the grad lab kitchen meals I made while doing my postgrad years.
 - I haven't given you the recipe because it's way too easy to need that.
 - It can be made entirely in a microwave. It makes 2 serving if you use the rice sachets, but if you use rice cups you can do a single serve more easily.

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- Take 1 pouch or cup of precooked microwave rice.
 - 1 small can of chicken or tuna
 - 1 small sachet of stir fry sauce (pref a 2 serving version, or split up a jar and freeze the extra in portions)
 - Frozen stir fry veges.
 - Heat the rice per the instructions
 - Mix the sauce and veges together and heat until piping hot.
 - Stir through the meat
 - serving on the rice.
 - You could probably also use black beans, chick peas, pre-made falafel or tofu, but I haven't experimented with those.
- Chocolate hummus – OMG, this is the best thing ever.
 - High protein, low sugar, sweet treat
 - It can even be made in small batches in a hand blender.
 - You have the recipe
 - I've brought some along for people to try.
 - Frozen fish parcels.
 - I've given you this recipe too
 - This one came from the UK show 'Eat Well for Less'.
 - It's got lots of veges and takes very little effort to make.
 - The idea for this one is to make a bunch ahead of time.
 - Do all the vege prep or buy pre chopped frozen veges.
 - Put it all together and freeze in meal packs for when you have no energy to cook.
 - If you use tinfoil they need to be cooked in the oven but seal better for freezing.
 - Baking paper means being able to microwave them, but you might want to wrap them in tin foil and/glad wrap to hold them together in the freezer.
 - You could potentially use brown paper bags, but they do get a not messy in the cooking process.
 - Meal prep tubs should work too.
 - Slow cookers make life much easier.
 - Get one that's much bigger than you need,

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- prep once and freeze ready to reheat meals from the left overs.
- Most slow cooker meals take very little prep and very little effort in the cooking.
- Just throw the ingredients into the pot, keep vege whole if you want, turn it on, and go back to bed.
- **Eggs:**
 - Take care with this one, because eggs bind the gut.
 - If you can walk around a bit, boiled eggs are a great food to have in your fridge.
 - They're incredibly easy to make in bulk, cooking 12 is the same as cooking 1,
 - if you leave them in their shells until you're ready to eat them, they will last at least as long as they would have lasted raw.
 - They are high in protein, so fill you up and keep you full while giving you slow release energy.
 - Always try to eat plenty of fibre when your activity levels are low, but even more so when eating eggs so you don't end up with painful constipation.
- Falafel is a good source of fibre, protein, zinc, and various other good things.
 - It can be frozen as cooked patties so you only need to reheat and serve.
 - I like to make my own from scratch over a few days, but mostly because I like to add extra veges.
 - If you're not keen on spending 3 days doing the various steps to make it, buy a pottle from the deli fridge or a powdered mix instead.
 - To cook it, don't be a purist, make your life easier by forming balls/patties and putting them on an oven tray (with some good non-stick baking paper) and baking them.
 - Make up the whole packet worth in one go.
 - The oven should be about 180°C and they'll usually need about 30 minutes, depending on how thick the shapes and wet the mix.
 - Set your oven timer to turn the oven off, if that's an option, and go have a nap.
 - The cooked falafel will last a few days in the fridge (I think mine last a good week), or you can freeze them for when you can't cook.
 - Serve with a dollop of unsweetened Greek yoghurt on a bagged salad. Easy

Slide 25 - Supplements

The slide features a dark blue vertical bar on the left with the word 'Supplements?' in white. To the right, on a light grey background, is a bulleted list of various nutrients and supplements.

- Vitamin B12
- Vitamin B5
- Zinc
- Potassium
- Magnesium
- Manganese
- Selenium
- Vitamin K
- Vitamin D
- Iron
- Copper
- Other:
 - Q10
 - BLIS K12
 - Ashwaganda
 - Green Tea extracts

- Supplements may be necessary to get your daily nutrient requirements – talk to your doctor about whether you might need to be tested for levels of or take these common or other nutrients.
- One I recommend everyone check out is Vit D3.
 - We don't get Vit D from very many foods unless it's been added, so we have to make it ourselves.
 - It is made in our skin cells from cholesterol and UV light, but only certain wavelengths of UV light work,
 - Don't make it in Winter in Aotearoa.
 - If you don't get out in the sun enough during the summer, or you wear a really good sun block when you do, you may be low in Vitamin D.
 - Most NZers are.
- D3 is an important hormone that helps regulate energy, sleep, mood, and various organ functions.

Slide 26 – No shellfish

Important side note

Eat like a royal

No shellfish!

It's like Russian roulette with food

- **Eat like the Queen... no shellfish.**
- You've probably heard of shellfish poisoning and toxic algal blooms, right?
 - Well, it turns out that one of the weird wee changes that occur with ME/CFS is added sensitivity to algal toxins.
 - We can be **more sensitive than the lab tests** and vulnerable to **illness even at "safe" levels.**
- **Not all shellfish will have algal toxins**, so a lot of the time you may be able to eat it without problems,
 - but that one time the toxin is present, even in low levels, you will feel like you're dying (and potentially could be, if you're really unlucky).
 - It's a bit **like playing Russian roulette.**
- I've had shellfish poisoning twice now. Both times I was sharing a plate of mussels with my husband's family.

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- The first time I got enough of a dose that by the end of the meal I was so sick I ended up vomiting in the bin outside the restaurant.
- The second time I had **a single mussel** from my mother-in-law's plate and spent the **next 48 hours in incredible pain**, my body too weak to get rid of the poison.
- **It took me weeks to recover each time.**
- That was when I looked up shellfish poisoning and discovered that people with certain medical conditions, including ME/CFS and fibromyalgia, are extremely sensitive to these algal toxins and should avoid shellfish.
- I discussed it with my GP and she confirmed that we should treat them like we're allergic.
 - Very annoying.

Mental Health and wellbeing

Slide 28 – Mental health and support resources

Mental health and support resources

Being chronically ill is really hard. It's ok to ask for help.

- MHERC (Mental Health Education and Resources)
- International ME/CFS community facebook groups
- ME/CFS Canterbury
- ANZMES
- Need To Talk – to talk to a trained counsellor any time for free, text or call 1737
- Reach out to those around you. It's ok to not be ok.

Trigger Warning: Discusses suicide risk.

- Get mental health support.
 - Being sick is really hard on the mental health.
 - You don't have to go through it alone.
 - According to a UK study I read on ME/CFS, people with this condition are approximately **7 times more likely take their own lives** than the rest of the population.
 - If that figure can be applied outside of the UK, that means NZ loses 15-20 people every year with ME/CFS to suicide. (sorry, I don't forgot where I read it. I can probably find it again if you want to read it)
 - When suicides are removed from the data, we have the same mortality rates and causes as anyone else.
- Support is available in many different forms. I've given you a series of links to these resources.
- MHERC have an online and physical library with lots of resources specifically relating to mental health and wellbeing. www.mherc.org.nz
They also have a couple of directories with numbers for emergency and long term support agencies. www.mherc.org.nz/directory/helplines
- In NZ you can call or text 1737 for free help, you don't need to be suicidal.
- There is also lifeline, anxiety helpline, grief counselling, online support groups (e.g. [ME/CFS Community](#), in person support groups like [Anzmes](#), [ME/CFS Canterbury](#) and [ME/CFS Auckland Support Group](#)).
- You can even send me a message if you can't think of anyone who would be better at it.

Slide 29 – Taking care of your mental health

Taking care of
your mental
health

- Learn to say “No”
- Let yourself off the hook, especially on bad days.
- Pets help, physically and mentally.
- When you don’t have much of a life, make the most of the life you have.
- Try to laugh as much and as often as you can.
- Keep a “To Do n e” list.

- Repeat after me. "No".
 - Learn to say no.
 - You don't need to give an explanation, no is enough.
 - **NO is a complete sentence.**
 - If they press say "**I can't**" or "**I don't want to**"
 - Repeat both answers until they get bored and wander off.
 - Or you can say: "**Thank you for thinking of me, and I'd love to, but I can't this time**" If you want to be asked next time.
 - "**Sorry, I can't**" or just "**no, I can't**" if you don't necessarily want to be asked again.
 - I like to use, in absolutely any situation, "**no thanks, I'm driving**" to confuse and deflect questions.
- **Also learn to ask for help.**
 - **Be gracious if told no and grateful if helped.**

- (Remember, they can say no too.)
- Both of these are hard but both are important to learn.
- Let yourself off the hook.
 - **No more verbs for you!**
 - You may feel like you don't achieve much, but sometimes keeping yourself going is a lot of work.
 - It's ok to need a "day off" to do even less.
 - Just vegetate in front of the tv, don't even take any of it in.
 - Eat bread dipped in something slightly runnier than bread, or eat baked beans straight from the can if that's what feels good.
 - Nap.
 - Don't chastise yourself, **that's too verby**, just stop. No verbs allowed.
- **Pets can help you.**
 - companions
 - Their presence is good for the mental and physical health too,
 - but that's not why I think they're important.
 - **Animals have difference sense capabilities to humans.**
 - We have comparatively excellent vision (unless your pet is a bird of prey), but poor hearing and smell,
 - and we barely registers electric, magnetic, and electromagnetic fields.
 - **An animal that lives with you will learn to recognise when you're pushing yourself too hard and will usually tell you so.**
- My last cat, **The Late Earl Roswell Barnapus Grey, Earl of East Side**, was forever putting me to bed or trying to get me to stop.
 - He would sit on my phone, or across my face, if he thought I wasn't resting properly.
 - He'd pin me down and refuse to let me out of bed when I was crashing.
 - He'd tell me off if he saw me getting dressed when going out was not a sensible activity.
 - Since he died, almost exactly a year ago, I'm having to relearn how to manage my energy level without him and I'm sh*t at it!
 - Try listening to your pets. They may be into something.
- When you **don't get to live much of a life, make more of the life you have.**
 - Sip your electrolytes from a fancy cocktail glass with a tiny straw and umbrella, like you paid \$18 for it.
 - Put on your prettiest pajamas to sit in the sun drinking your salty cocktail.

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- Add some nice music.
- Pretend it's a fancy soiree.
- Serve your frozen dinner on a fancy plate
- light a candle.
- Had a shower and need to dry and comb your hair or put on moisturiser?
 - Make the space special - **you're a star getting ready for the Oscars** (but inexplicably doing your own hair and makeup?).
 - **Make your life an event.**
- Laugh. We all know it helps, so make a conscious effort to do it.
- A **To Done List** lets you look at what you achieved in the context of your day.
 - Maybe you're feeling really good today and manage to run errands, clean the bathroom, and read a chapter of your book.
 - Maybe you are feeling really ill and are bed bound, but you managed to eat 2 meals, meditate for 5 minutes, and listen to 30 minutes of audiobook.
 - Maybe you changed your underwear for the first time in days. **It all counts**
 - When you look at what you achieved, **not comparing it to what you wanted to get done**, you reframe things into a less depressing picture.
 - Recognise the effort you made.

Slide 30 – More on caring for your mental health

More on caring
for your mental
health

- Develop good sleep hygiene.
- If you're struggling to solve a problem, step away and reconsider the question.
- Avoid the hopes up – let down cycle by being interested but skeptical.
- You do not need to justify your existence; you already exist.
- Let yourself grieve.
- Forgive yourself.

- Develop good sleep hygiene.
 - I have a method I use, I can share it later with anyone who wants to hear it.
- If you're struggling to think how to do something or to solve a problem, stop and rethink the question.
 - You may be trying to redesign a square peg to get it to fit in the round hole and failing to see the existing round peg available to you.
 - **Stepping back** and looking at the question you're asking can help see that the problem isn't what you thought it was.
- An example... 2006... I had come home for xmas. I was **at the mall** with my family doing our gift shopping.
 - My feet and legs hurt.
 - I wanted my flat shoes.
 - I couldn't go home to get my flat shoes.

- My boyfriend would drive from Riccarton to Brighton and back to bring me my shoes.
- All I could think of to solve it was different ways to get my shoes to me, but none worked.
- How I saw the problem: I need my other shoes.
- The actual problem: I can't walk in these shoes.
- Better solutions, as posed by my far less exhausted sister as I sat on the floor of Farmers Manchester department crying:
- Is the problem the shoes or the walking?
- **Shoes** - Buy a cheap pair of footwear (jandles, slippers, house shoes, it doesn't matter)
- **Walking** - Borrow an electric or manual wheelchair from the mall information desk.
- When we are tired we don't problem solve as well as when we're refreshed and alert.
 - We get stuck to an idea because our brains are too tired to see the real issue.
 - Take a break from trying to solve it, and/or asking someone to help you find the solution.
 - Even explaining the problem can sometimes help you see that the detail you're stuck on isn't the actual problem at all.
- Be sceptical of anyone who promises a cure, especially if they want money for it.
 - Don't get your hopes up too much over the promises as they tend to be like Icarus'' wax wings - only able to carry you so high for so long before they send you crashing to the rocks below.
 - Although, like Icarus, you may find they can liberate you, if you remember never to fly too high.
 - There are a lot of people out there selling treatments and promises of a cure, from supplements and stem cell treatments to lifestyle and psychologically based therapies.
 - Even a lot of off label drugs are promising a lot at the moment,
 - but the one thing they all have on common (for now at least) is that they don't permanently cure anyone of anything beyond their attachment to money.
- Certainly a lot of things help,
 - some may take you back to a healthy baseline for a while (before they stop working and you crash land),

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- or give long term small improvements while you continue taking them,
 - but while our metabolic systems are functioning abnormally, they are only working like an air pump on a deflating tyre.
 - I do hope a cure is found, but I'm not going to get excited over any promises of one until I see it actually work.
-
- You do not need to justify your existence; you already exist.
 - Do you berate a rock for not being rocky enough?
 - Do you just a fish by its ability to paint landscapes?
 - Do you look at the moon and stars and say they're not bright enough?
 - **There's something you can do that noone else can do - be you.**
 - Just allow yourself to be the you that you are, not the you that you once were or hoped to be.
 - You're here, now, live the life you have even if it's not the one you had planned.
 - Make the most of it because you don't get another.
 - **Let yourself grieve the life you had**, the life you had planned and everything else you've lost.
 - **Forgive yourself.** None of this is your fault, it is just bad luck and that sucks.

Questions

Any Questions?

Any tips or hacks of your own?

Additional material

Slide 32 – Sleep hygiene

Sleep hygiene

- Choose a sleep trigger, keep it 'sacred'
- Set your alarm for a reasonable time to wake up
- Do your nightly routine at a reasonable time
- When you feel you're ready to go to sleep (and only then), engage trigger.
- If you're not asleep within about 15 minutes (subjective guess will do) REMOVE the trigger and get up
- Wait until you feel sleepy before reengaging the trigger.
- Repeat until you fall asleep or the alarm goes off
- GET UP with the alarm, even if you had no sleep at all.
- Remove the trigger immediately.
- Repeat next time you want to sleep.

It's hard to do this when you live in bed. It's especially hard when disordered sleep is part of your pathology, but doing what you can will help.

Traditionally sleep hygiene means keeping your bed for sleep and sex only. If you can do this, moving from your night bed to a day bed or day resting spot, that's brilliant. Do that and keep the sleep space 'sacred.' If you can't, you need to find something that will work as a clear, physical and sensory, distinct and unmistakable trigger that you will use to change states from awake to asleep to awake.

Years ago, when I first discovered sleep hygiene, I worked with a doctor to create a trigger. I was living in a shared flat, in a very small bedroom, so my bed was also my workspace and my living area. I couldn't avoid using my bed when studying and as the lounge was shared with up to 4 other people, I needed to be able to use it as a living area too.

We settled on my pyjamas as a trigger. I had 3 sets of flannel pyjamas for sleeping. I would put them on immediately before settling down to sleep (no tv, no reading, pjs go

on and lights go out), and take them off immediately on waking. I was allowed to go to the bathroom and back, but nowhere else. If I needed to do anything else, I had to get dressed first.

These days I use sleep headphones that also work as an eye mask. I don't use these headphones for anything except my sleep sounds. I also have headbands I use without the speakers, which do the same job.

Training your body is hard. It can take a few torturous nights, but it's important to be consistent.

- 1) set your alarm for a reasonable time to wake up. Don't think about how much sleep, just what time you want to get up. You will use this wakeup time every day until the habit is formed.
- 2) do your nightly bedtime routine but DO NOT engage your trigger yet. Turn off screens, lower the lights, do something that isn't stimulating.
- 3) When you feel like you might be able to fall asleep, only then should you bring in the trigger. Put on your pjs/headphones/get into bed and turn out the light.
- 4) you probably won't fall asleep. If you're not asleep within 15 minutes, get up, remove the trigger and go and do something else until you feel sleepy again.
 1. Repeat steps 3 and 4 until you either fall asleep or your alarm goes off and you get up for the day, whichever happens soonest.
- 5) get up with the alarm and remove the trigger.
- 6) DO NOT NAP. Not until the trigger is set up. It might be a hard few days, but it's important that you are very tired next time you go to bed.
- 7) when bed time approaches, start again. You should be very tired now and your body will give less of a fight.

It may take a week or more of sleeping only a few hours each night, but with practice your body will learn to go to sleep and stay asleep while the trigger is in place. When it has the habit truly down, you can use it to turn a nap in and off.

I have my system trained into the headphones now that I must take them off as soon as I hear my alarm, because if I'm still wearing them when I turn off my alarm I will immediately fall asleep again until they fall off.

You can also do this when you're feeling sleepy already, if insomnia isn't a problem but sleep times and waking are - apply trigger, set alarm, remove trigger when you wake up.

Slide 33 – Burrito Roll (for Duvet Innerers)

Burrito Roll

- Removing the old cover can be done as a reverse of putting the new one on
- Lay the clean cover in the bed, inside out and face down.
- Lay duvet on top, matching corners
- Roll or fold the duvet and cover all the way from top to bottom.
- Turn the cover right way out over the burritoed duvet
- Double check corners are still matching up
- Close the hole
- Unroll your burrito

- You remove the old cover by pulling it back, turning it inside out as it pulls off. This means you wash it inside out, which saves effort later and protects the outside of the cover from fading and damage.
- Lay the clean cover on the bed inside out and face down. I put the open end at the bottom, the video shows it at the top. I'm not sure how she's unfolding it to get that to work, but it's minor. She also attaches the duvet to the cover, which is an extra step that I don't bother with either.
- Align the corners and edges.
- Roll or fold the duvet and cover from the closed end all the way to the open end of the cover, like a burrito.
- This is the hard bit. Turn it inside out. You need to flip the cover inside out over the duvet. She describes it like folding socks.
- When it's all flipped the bottom edge of the duvet and cover will pop loose and you can do it up. Double check your corners have stayed in place.
- Now unroll the duvet burrito so it's nice and flat on the bed.

Slide 34 – Chocolate hummus

Chocolate hummus

- Makes about 2-3 cups, which will keep for about 4 or 5 days in the fridge if it lasts that long.
- 1 can black beans or chick peas, drained, but hold onto the liquid.
- 1/4-1/2 c cocoa powder (to taste). The darker Dutch type is good, but any unsweetened baking cocoa is good.
- 1/4-1/2c (or equivalent - to taste) sweetener of choice (honey, maple syrup, golden syrup, agave, Apple sauce, splenda whatever you fancy).
- A little bit of fat - I often leave this out and don't miss it, but up to 1/2c of peanut butter, nut butter, avocado, coconut fat, tahini, melted cocoa butter... whatever you like for taste and texture.
- Pinch or 2 of salt.
- 2 tsp essence of choice (vanilla, orange, mint, almond, raspberry...)
- Flavour additives:
 - Any spices you want to add (I don't use oils if I'm adding spice, but that's just a flavour preference thing) - ginger. Cinnamon and cayenne. Extra sea salt. Instant coffee (it's a spice!). Cardamom...
 - Anything you want to add for texture and flavour - choc chips, freeze dried berries, crushed nuts, coconut...
- Stick everything except the 'flavour additives' into a food processor and whizz it smooth. You may need to add a little extra bean liquid or water to some ingredient combos. You're aiming for a pudding/ganache/hummus type texture.
- Stir in your additives.
- Try not to lick the blades of the food processor when cleaning up.

Chocolate hummus. It's high in fibre and protein, infinitely customizable, fast, easy and soooooo yummy.

I'm not a precise cook, so it's all a bit "about that much, usually, except when I feel like this much instead." It's pretty hard to go wrong though.

It makes about 2-3 cups, which will keep for about 4 or 5 days in the fridge. I can easily eat that much of it, but to slow myself down I will make it in smaller batches, about 1/4 to 1/2 can at a time, in a string pull hand blender from kmart, which usually last me 24-48 hours.

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- 1/4-1/2 c cocoa powder (to taste). The darker Dutch type is good, but any unsweetened baking cocoa is good.
- 1/4-1/2c (or equivalent - to taste) sweetener of choice (honey, maple syrup, golden syrup, agave, Apple sauce, splenda whatever you fancy). I prefer maple syrup and like it less sweet.

Lorem Ipsum Life Hacks for ME/CFS

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Stir in your additives.

Try not to lick the blades of the food processor when cleaning up.

Slide 35 – Instant Porridge

Instant Porridge

- A couple of cups of rolled oats and add a bunch of stuff I like in porridge,
- some milk powder,
- 1/4 c per cup of oats, Spices,
- Brown sugar. I use about 2T per cup of oats,
- usually, Dried fruit, again, if you don't like it, leave it out. I have been trying to find chopped up pieces of dried apple or feijoa, but so far I've mostly used the mix you get for fruit cake. Fruit cake mix needs to go in the food processor because it sticks together too much to add later, other varieties of chopped dried fruit can go in at the end..
- Throw everything in the food processor. Leave out the fruit if it's free flowing, unless you want it cut up smaller. Chop that porridge into dust. I usually leave it a little chunky, but only because I'm impatient. Finer = more porridgey and less powdery. Store in A large, air tight jar with an easy to open lid
- To make it, scoop about 1/3c into a bowl and add at least 1/2c boiling water and stir, add more if it's gluggy. If you want to use cold water and a microwave, your guess on timing is as good as mine - 60 seconds, 90?

Slide 36 – Fish Parcels

Fish parcels

- Frozen fish fillets, unbattered, one per parcel. Leave in the freezer until you are ready to add them.
- leek, chopped into rings
- Peas, carrots, and beans, or frozen mixed veges.
- Potato or kumara chopped into sticks (don't peel them, they're fine)
- You could also add capsicum, pumpkin, seeds, whatever takes your fancy.
- lemon slices or some fennel if you have it.
- Tinfoil or baking paper - quite big pieces.
- Lay out your baking paper/foil, 1 per parcel.
- Put a handful of potato/kumara pieces on each one. Then layer on your over veges with the leeks on top. Place frozen fish fillet on top, arrange lemons on top of fish. You should now have an attractive mound of veges with a slab of lemon covered fish on top.
- Wrap the parcels and seal them well. If you're using paper and plan to microwave them, put them in a brown paper lunch bag after wrapping, to keep them together. Pop in a plastic freezer bag to keep them from getting freezer burn. Freeze until needed.
- To cook, Microwave each parcel, from frozen. on high for 10 minutes (in the paper bag), or bake on a tray at 160°C for 45 minutes (the tray is to catch juices). I haven't tried defrosting them first, but it should still work in the oven and be faster. Check if the fish is cooked. If not, give it a bit longer. Mine usually take about 60 minutes in the oven.

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