

Living Well with Epilepsy

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Goals and objectives

- Discussion of some of the challenges, frustrations and barriers to life with epilepsy
- Opportunities for audience participation and kvetching
- Recognition and solutions to some Barriers to Living Well with Epilepsy
- End hopefully a bit more optimistically

What does it mean to live well

- What are the target goals?

Target goals for other things

- Diabetes: HgbA1C <6.5% represents good control, sometimes 7 or 8
- Cholesterol: LDL less than 70, maybe 100, not more than 115
- Complete a college education: 4 years
 - Fly in Four
- Lifespan of a hot water heater: 8-12 years

Target goals for living well with epilepsy

Epilepsy is a diverse disorder, so goals for a given individual will vary

- Seizure free
- No side effects
- Able to work
- Able to drive
- To go to sleep over camp
- No problems with memory
- Medicine that is affordable
- Share with us your other goals



Medical Care: An essential Cornerstone of Epilepsy Care

- Do you like your doctor/ care provider?
 - Doctor listens to me?
- Can you get to the clinic
- Can you afford the visits
- Do you feel like you can speak up if there are issues of affordability

It isn't easy being a Neurology patient

- Average wait time for new appointment: 30 days
- Average wait time for follow up 20 days
- General Neurologists may not be as adept to the nuances of complex epilepsy
- Making that critical connection with your doctor:
 - 33% of US Neurologists are women
 - Mean Age 51
- Primary care doctors: some do not have the comfort level with this disease nor the time

<https://www.aan.com/PressRoom/Home/PressRelease/1178>

Burton, Adrian, How do we fix the shortage of Neurologist April, 2018 Lancet Neurology DOI: [https://doi.org/10.1016/S1474-4422\(18\)30143-1](https://doi.org/10.1016/S1474-4422(18)30143-1)
AAN Annual Compensation Report

Patient Focused Care

It is ok to make change

- It is ok to speak up
- It is ok to switch doctors
- It is ok to talk about the expense of treatment, visits, family and personal constraints
- Use electronic tools, such as the patient portals to potentiate care

Electronic Patient Portal



Communicate with your doctor

Get answers to your medical questions from the comfort of your own home



Access your test results

No more waiting for a phone call or letter – view your results and your doctor's comments within days



Request prescription refills

Send a refill request for any of your refillable medications



Manage your appointments

Schedule your next appointment, or view details of your past and upcoming appointments

SIGN IN

[Forgot Username?](#)

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New User?

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Patient portals

- Sometimes this wonderful technology doesn't work at all
- If you haven't heard back from a human, make a telephone call.
- Stuff gets sent, but not received
- Doctor sends the prescription to the pharmacy:
 - Pharmacy says it is not there
- This is a great source of stress

Insurance Pre-Approval *Medicines or Tests: Denied!*

- It's nothing personal
- Tests and medicines are denied for people with all kinds medical conditions.
- The insurance company throws the doctor under the bus
- **How to Appeal an Insurance Denial: 9 Steps to Success**
 - <http://complexchild.org/articles/2015-december/appeal-insurance-denial/>



Complex Child



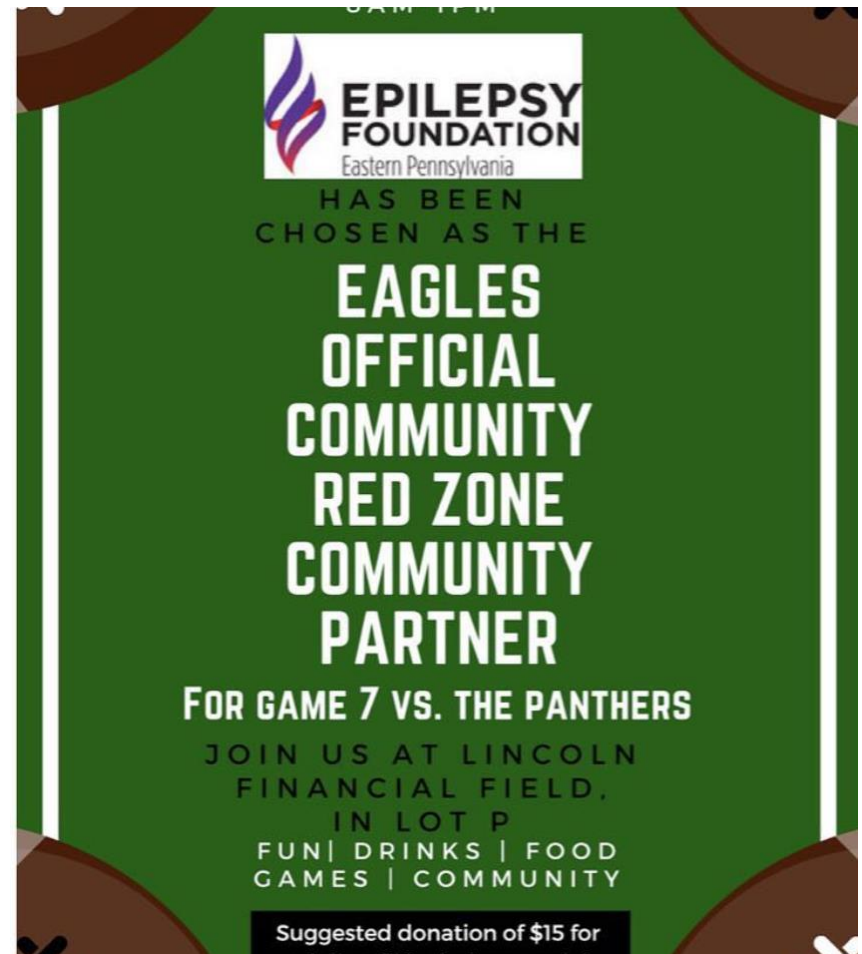
I'm OK! That bus you threw me under wasn't that heavy.



someecards
user card

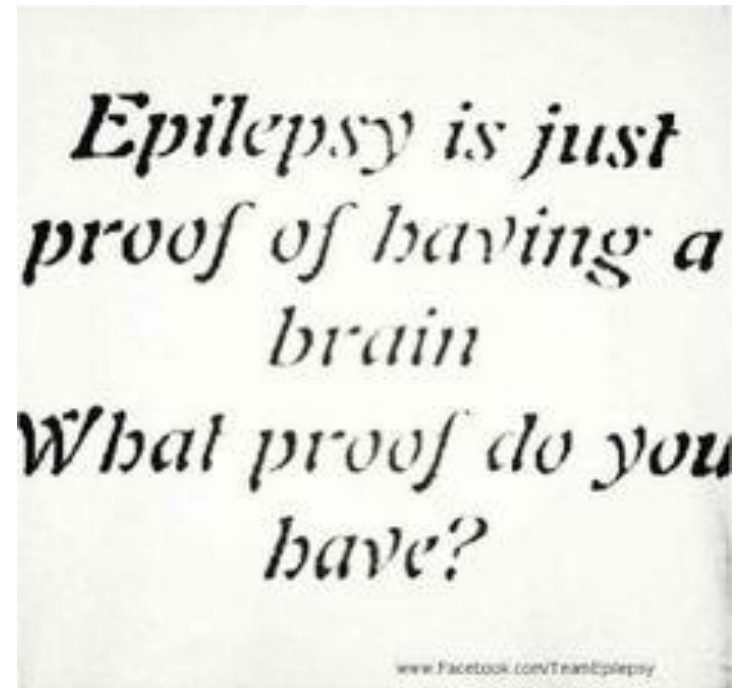
Who is on your care team

- Family
- Friends
- Co-workers
- Teachers
- Clinical team
- Epilepsy Foundation
- Philadelphia Eagles



Recognizing those who are not on your team

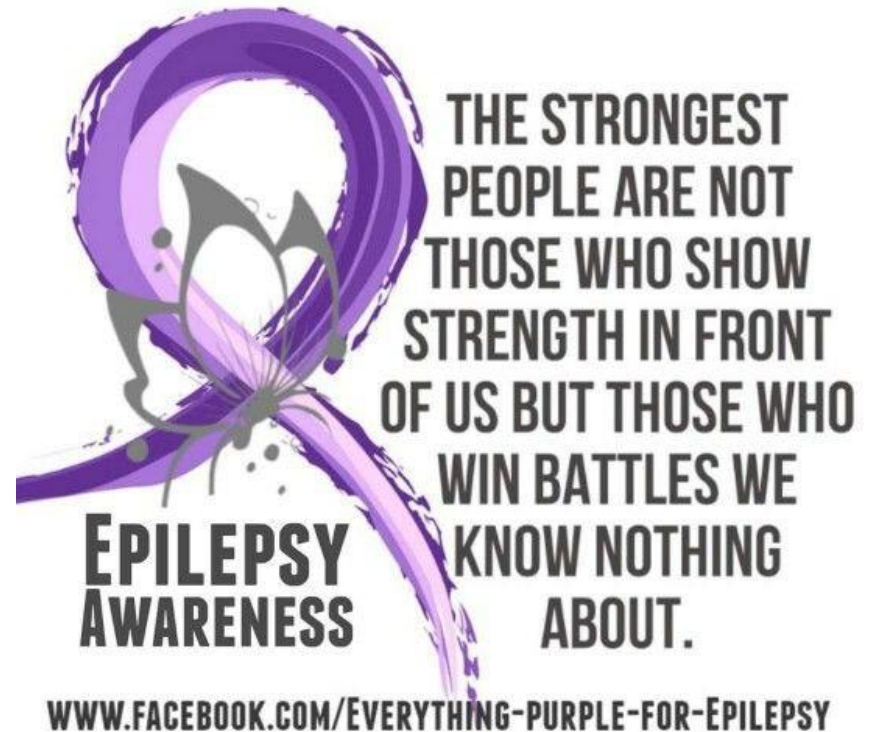
- Ignorant
 - Need education
- Bias
 - Need education, but maybe you don't have the energy to educate
- Well meaning, but should think before they speak
- Just not nice



Stigma and Epilepsy

Two kinds of stigma

- Externalized Stigma:
 - Experiencing bias from others
- Internalized Stigma:
 - Feeling oneself as if you are not as good.
- Having these bad experiences is NOT ok, important to talk to the people who are ON YOUR TEAM



Driving & Epilepsy



- Pennsylvania is a mandatory reporting state
- People who have had a seizure and visit an emergency room are likely to be reported.
- Immediately after a seizure, you may NOT recall that the ED doc told you that you would be reported until you received a lovely notice from the DMV
- For more information relating to Medical Reporting, visit <http://www.dmv.state.pa.us/centers/medicalReportingCenter.shtml>

Driving and Getting Around with Epilepsy

- Some seizures meet waiver criteria
 - “Provoked” due to a clear, identifiable, one time cause
 - Strictly nocturnal
 - Sufficiently long aura prior to 100% of seizures
- Citizens of the Commonwealth have the right to appeal the decision

Getting that unpleasant notice from the Commonwealth

- Everyone has trouble processing this kind of bad news
- Brilliant people have trouble figuring out what the letter wants them to do.
 - Some people can keep the license, but only as a form of identification
 - Some people are told to turn in the driver's license and get a PA non driver's ID
 - Some seniors feel that as long as they have that card in their possession, they are good to go!

If you never had a license

- Must be seizure free for a year
- Must bring a form to your doctor's visit for the doctor to sign in your presence
 - So, you can't just drop it in the mail!
- It was raining, you took the bus, with your cranky 2 year old and the form is on the kitchen table
- The form is online from the Commonwealth
 - Assuming the website is working

When you are seizure free 6 months

- Call the staff in Harrisburg a few days in advance to tell them to expect your paperwork
 - Phone 717 787-9662
 - Fax 717 705-4415
- Communicate with your doctor at the 6 month point
 - On a Monday-Friday
- Your doctor sends forms back to Harrisburg
- You should have your license back in a day or two
- Audience Participation Moment: Which DMV is the nicest to visit?

Epilepsy, Work and School

ADA: Americans with Disabilities Act

- The **Americans with Disabilities Act (ADA)** became law in 1990. The **ADA** is a civil rights law that prohibits discrimination against individuals with disabilities in all areas of public life, including jobs, schools, transportation, and all public and private places that are open to the general public.



Epilepsy is a condition **covered** under the ADA

- Epilepsy is a physical impairment that substantially limits one or more major life activities, including neurological functions during a seizure. **An episodic impairment, such as epilepsy, is a disability if it substantially limits a major life activity when active.** 42 U.S.C. § 12102(4)(D). A person with epilepsy has a disability within the meaning of 42 U.S.C. § 12102 and 28 C.F.R. § 36.104.

Yes, you can go to camp with epilepsy

- Under title III of the ADA, **no person who owns, leases (or leases to), or operates a place of public accommodation may discriminate against an individual on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of a place of public accommodation.** 42 U.S.C. § 12182(a); 28 C.F.R. § 36.201. Discrimination includes a public accommodation's failure to make reasonable modifications in policies, practices, or procedures when necessary to afford its goods, services, facilities, privileges, advantages, or accommodations to an individual with a disability, **unless the public accommodation can demonstrate that making the modifications would fundamentally alter the nature of the services.** 42 U.S.C. § 12182(b)(2)(A)(ii); 28 C.F.R. § 36.302.

The ADA and ADAAA can protect you on the job

- EEOC – enforces the ADA law
 - What those with epilepsy may need
 - When an employer can ask about epilepsy
 - How to handle safety concerns
 - How an employer may ensure no harassment in workplace
- <https://www.eeoc.gov/laws/types/epilepsy.cfm>
- ADAAA – Amendments to the ADA to ensure that individuals with conditions treatable by medication can still be considered qualified individuals with disability
- https://www.aesnet.org/clinical_resources/practice_tools/employment_resources/workplace_accommodation

https://www.aesnet.org/clinical_resources/practice_tools/employment_resources/workplace_accommodation

A person with epilepsy can ask for Accommodation

- You must disclose your condition in the work place
- Many times, people tell me that they were pressured to leave a job, rather than ask for accommodation
- That is not legal

Reasonable requests

- Memory problems/verbal memory:
 - Ask that instructions be written down as well as being given verbally
- Long shifts - can you be offered a shorter work time?
 - Often seen in health care
 - Breaks, options for day shift vs. night
 - Accommodation needed for women with epilepsy and new babies
- Are flexible hours an option in your line of work?
- Should you tell your co-workers?
- Would you want your employer to arrange for epilepsy awareness training for your colleagues

UK has a ten step guide for employers to help a person with epilepsy remain in the workplace

- Employer should understand the characteristics of the seizures
- Safety plan in case of a seizure
- Work place, work schedule should be developed to minimize seizure triggers
- Dignity: must have their own locker with place for medicine, pillow and change of clothes
- Access to bathroom with a safety cord
- Evacuation plan in case of emergency that fits their ability to exit the work place.

From Canada

ACCESSIBLE
VERSION

English

Française



This toolkit will provide **training** and **information** on how to **support co-workers, clients and customers with epilepsy in the workplace.**

Understanding Epilepsy in the Workplace



In 30 minutes you will be able to answer the question, "How can I help"? This is a course for employees and co-workers

world
envi

+ more info

Seizure Safety



These unique and original videos will teach the user how to recognize the most common seizure types and how to

provi
assi
setti

+ more info

place

Helpful Resources



Here's the home of all of the just-in-time Helpful Resources for HR professionals, managers and supervisors, recruiters, occupational health and

browse



For more information:

1-866-epilepsy



United Way | Member Agency
Charitable N° 107306912RR0001



An Enabling Change Project
with the Government of Ontario

The material contained in this website provides a thorough overview of epilepsy and employment but is in no way presented as the authoritative guide to management of epilepsy in all its forms.

CONNECT WITH US



The ADA also protects students

- College students who are otherwise seizure free and doing well (as well as those who need some help) can utilize the ADA
- It may be an unreasonable expectation for a student with epilepsy to have three final exams in a day
- A student with epilepsy might need reasonable accommodation to take one exam on another day

College and High School Students

- In my personal experience, faculty at Temple have kind, happy to help students.
- Student health asks - what can we do to keep this young adult healthy?
- Some college students get a Neurologist near the University
- Athletes with epilepsy & their trainers have a travel plan

Planning for College

- Going to College with Epilepsy is like taking one extra course
 - HS senior starts taking responsibility for their own medicines before college starts
 - Parents hand over the reins
- Plan of care to make sure we have medicine at the University
- From Philadelphia, we can call in a refill to the CVS at State College for that freshman who is out of medicine.

Transitioning to College

The epilepsy care provider needs to talk to the young person about:

- Sleep
- Alcohol
 - We never condone under age drinking but young adults need information
- Sex and contraception
- Self efficacy and advocacy
- Privacy
 - Health care information is confidential

Transition of Care

- The term refers to a teen transitioning from Pediatric Epilepsy Specialist to Adult Neurology
- There is also the Transition, as the young person takes control of care, regardless of who the doctor is
- Parents need to allow that independence

Alcohol

Common misconception: Seizure medicine and Alcohol = antabuse effect

Some advice:

- One drink feels like two, two drinks feel like four
- No more than two drinks in 24 hours, no more than 5 in a week
- For women, no more than one drink in an evening, for men: two

Excuses when offered a drink

- I am taking medicine- then say nothing else
- Thanks, I am the designated driver
- I am training for... choose your event
- I am on a cleanse of lemon water and chili pepper (specific diet)
- Thanks, but my coordination is bad enough as it is when I'm sober
- Just get a red Solo cup and carry it around

MEMORY

It is often a problem

- It is important to remember some things- like picking up the kids from school, paying taxes on time
- Often, memory issues are embarrassing, annoying
- In professional and academic life, there may be work-arounds
- Work-arounds in family life too...

Memory guidelines

- Follow a set routine
- Adapt your surroundings
 - Organize- always put things back in the same place
 - Less stuff, less to remember
- Use memory aids (can be simple or complex)
 - Note book
 - Smart phone
 - Epilepsy specific apps such as Seizure Tracker
- Mnemonics
 - Pairing a word with a visual image or a phrase
- De-stress: Improve your well being
 - No one can remember anything if too tired or too anxious

Memory issues in social circumstances

- It isn't necessary to share that one has epilepsy, but it is helpful to acknowledge to others
- I am sorry, my memory isn't the best, but...
- My ears are not what they used to be...
- Forgive me, this is not the best day for my brain, remind me...
- When I have had a headache, I am a bit fuzzy afterwards
 - You had the headache after a seizure, but you can leave out the seizure part....

Memory/Aging/Health

- Being well means eating well
- Eating well can reduce risk of high blood pressure and diabetes
 - Heart healthy diet
- Keeping diabetes and blood pressure under control is important for everyone, but especially for people with brain problems
- Don't smoke
- Exercise

Exercise

- Important for physical health: heart health, bone health, reducing risk of osteoporosis
- Good for balance, reducing risk of falls
- Stress reduction
- Exercise program should enable you to turn off the chatter and de-stress for an hour
 - Consequently, there is a difference between spending 40 minutes on the exercise bike while reading a text book vs. going to Yoga class
- Time for your physical, emotional and spiritual wellbeing

Epilepsy, Exercise, Safety Concerns

- Depends in part on the sport/ activity
- Carry ID if you run or cycle
 - Medical alert bracelet, tag or USB key in some cases
- Wear a helmet when bicycling
- Never swim alone
- Complete the safety information on health intake form at the gym
- Stay hydrated
- Supplements: Use caution (don't take them) in regard to training supplements
 - Contain Caffeine, stimulants

Sleep

- Get enough sleep!
- Lack of sleep worsens seizure control and makes it hard to remember things!
- Not enough sleep makes everything more difficult
- Don't be afraid to modify schedule to get enough sleep

Young adults:

- You can take an Uber home from the party
- Academic schedules can be tailored
- Parents with newborns need to sleep
- Sleep is more fragile after the age of 40
- Put away the electronics well before it is time to go to bed
- Consider reading on paper rather than a screen later at night
- Night settings on your phone or tablet are available

Epilepsy and Depression

- One third of people with epilepsy will suffer with depression
- Depression can impact anyone, and also bears stigma
- Royal mission: “to ensure that people feel comfortable with their everyday mental well being, feel able to support their friends and families through difficult times, and that stigma no longer prevents people getting the help they need. “



Prince Harry

“The experience I have had is that once you start talking about it, you realize that actually you’re part of quite a big club,”

Epilepsy and Spirituality

- Religious community can be a part of your support network
- Unconditional acceptance of who you are
- An affirmation:
 - “I deserve and accept a physical, mental, and emotional health into my life right now.”
- More inspirational stories and advice:
 - Takeonepilepsy.com
 - From Greenwich Bioscience

Finding Support in your community or online



**EPILEPSY
FOUNDATION**
Eastern Pennsylvania



**EPILEPSY
FOUNDATION**

CURE

CITIZENS UNITED FOR
RESEARCH IN EPILEPSY

seizuretracker.com
be aware. track it.



North American Antiepileptic Drug Pregnancy Registry
<http://www.aedpregnancyregistry.org/index.htm>

Epilepsy self management: Finding support and information online

- There is little data on the value of on line support for management of women with Neurological issues in the reproductive years
- “Physicians should embrace inquisitive patients. **Online investigation of disease and treatment counters what many patients feel as a loss of autonomy. It may help them regain a sense of control during a scary and sometimes helpless time.**” Martin R Weiser, NYT 8/29/2016
- From a GI study “over 90 percent of patients searched the internet for information; most patients landed at WebMD, the Mayo Clinic website or Wikipedia. While these sites can serve as useful places to obtain general information, **they do not contain enough nuanced and individualized information to allow patients to make fully informed decisions. They cannot properly weigh the benefits and risks of a specific therapy in the context of a patient's unique circumstance.**” [Arun Swaminath](#) NYT 8/29/2016
 - Use of online sources did not impact patient willingness to accept new therapies
 - In other words, “Patient Dr. Google” can still make best decisions, once she has met with her physician

Online patient support groups

- Social ties forged in online spaces provide the basis for performing relevant self-management work that can improve an individual's illness experience, tackling aspects of self-management that are particularly difficult to meet offline.
- Membership in online groups can provide those living with a long-term condition with ready access to a self-management support: illness, workforce and emotional support.
- The substitutability of this work may be particularly important to those whose access to support offline is either limited or absent.
- Furthermore, such resources require little negotiation online because information and support is seemingly gifted to the community by its members.

Technology and Epilepsy

- It is easier to connect to the epilepsy community if you will use the internet
- Smart phone/tablet/computer
- Seizure calendars
- Apple watch – epilepsy app



- Embrace Smartband for epilepsy monitoring: Seizure monitor watch

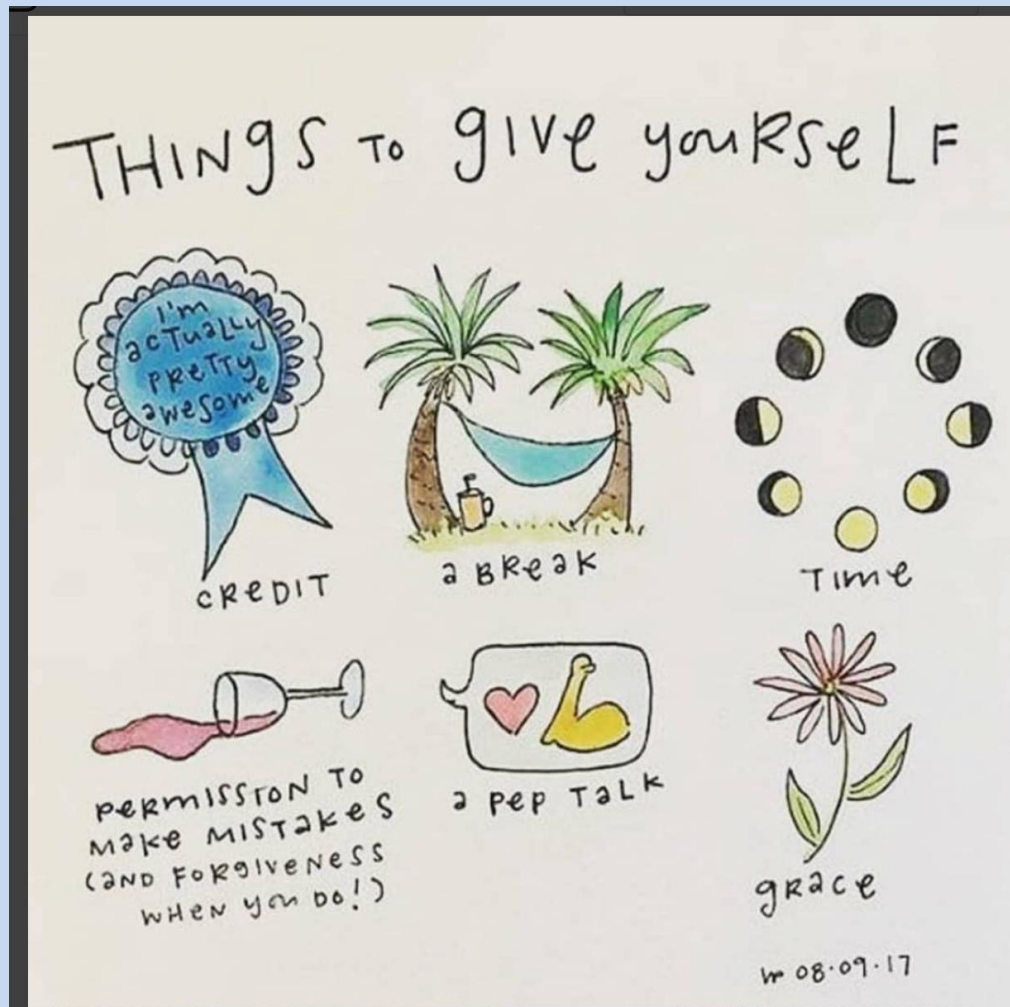


https://www.empatica.com/?gclid=EAlaIQobChMllpOMrluY3gIVhjlCh1Fdgp6EAAYASAAEgKj9_D_BwE

Some people are just born fabulous.



In conclusion:



[EFEPA Don't be afraid to give yourself things. #epilepsy #epilepsyawareness #selfcare #love #efepa](#)

Posted on the EFEPA Instagram account