Epilepsy Resources for Life Care Planners

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Abstract

This paper is focused on providing resources for life care planners who are developing life care plans for people with epilepsy It includes a review of the condition, it's prevalence, impacts on the lives of people living with it, mood effects, mobility effects, educational effects, and vocational effects. The list of resources include programs housed across the United States, technological applications for personal use, and resources for educational challenges. Resources for personal education are listed.

Keywords: Epilepsy, seizures, resources

Epilepsy is the "fourth most common neurological disorder" in the United States (US), (England et al., 2012; Schachter et al., 2014), yet some individuals living with epilepsy lack knowledge about their condition, including how to manage it (Mameniskiene et al., 2015; Sajatovic et al., 2019). Epilepsy includes seizures that can lead to a social stigma because of the public's knowledge gap (England et al., 2012; Thijs et al., 2019). By disseminating knowledge to the public, the stigma against epilepsy should be reduced. Additionally, everyone with a diagnosis of epilepsy has a right to quality healthcare, education, and employment.

Epilepsy is considered to be a "spectrum of disorders" to include different seizure types with varying known and unknown causes as well as comorbid conditions (England et al., 2012). Individuals receive the diagnosis of epilepsy when two or more seizures have occurred (Centers for Disease Control and Prevention, 2020b). During a seizure, complex chemical changes in nerve cells cause an imbalance, which provokes a "sudden surge of electrical activity in the brain" (Schachter et al., 2014). Some types of seizure can be observed, and seizure activity typically affects the person's behavior for a short time (Schachter et al., 2014). Rehabilitation professionals develop life care plans for individuals who are diagnosed with epilepsy.

In the US, it is estimated that there are 150,000 new diagnosed cases each year and 1 in 26 people will live with epilepsy at some time in their lives (England et al., 2012; Epilepsy Foundation, 2020b). People with epilepsy include all ages, genders, socioeconomic backgrounds and ethnicities (Epilepsy Foundation, 2020b). Thijs et al. (2019) reported a global estimation of 70 million people affected by epilepsy. Unfortunately, in 1 of 10,000 individuals newly diagnosed with epilepsy, sudden unexpected death in epilepsy (SUDEP) will occur (England et al., 2012). In 2012, it was reported that the direct medical cost of

epilepsy in the US was 9.6 billion annually, which excluded the indirect costs from losses of quality of life and productivity (England et al., 2012).

Impact of Epilepsy

Individuals with epilepsy face many daily life challenges. The challenges include significant mental health issues due to problems such as lack of social support, embarrassment, fear of social rejection or having a seizure and injury. Changing medication doses can at least temporarily increase side effects (Epilepsy Foundation, 2020b). Also, fatigue is reported especially for those with uncontrollable seizures (Epilepsy Foundation, 2020b). Epilepsy affects individuals differently, but they experience hardships in the various environments in which they interact such as schools, social situations, jobs, community events, and in their homes.

Epilepsy-related challenges can be especially present for those with uncontrollable seizures, or refractory epilepsy, because seizures are unpredictable. Sirven (2021) reported that 20 to 40 percent of individuals with epilepsy, or approximately 400,000 individuals, are likely to have refractory epilepsy with medication resistance. (Epilepsy Foundation, 2020d) reported that one-third of these individuals live with uncontrollable seizures. The Centers for Disease Control and Prevention (2020a) created the Managing Epilepsy Well Network (MEW) in 2007 to address self-management caused by the challenges of epilepsy. The MEW uses Emory University partnered with Dartmouth College as the coordinating center with New York University, the University of Arizona, the University of Iowa, and the University of Washington as collaborators for assisting those living with epilepsy.

Mood Effects of Epilepsy

Epilepsy Foundation (2020a) reported rates of 25 to 55 percent of depression in individuals with epilepsy. Kanner et al. (2012) and Fiest et al. (2013) had previously confirmed that epilepsy was significantly associated with depression; although there can be a lack of identification and treatment for depression (Epilepsy Foundation, 2020c). Additionally, anxiety is reported in approximately 20 percent of individuals with epilepsy after being diagnosed, due to seizure activity, or other reasons (Epilepsy Foundation, 2020c; Hingray et al., 2019; Wang et al., 2019). Mula and Sander (2013) reported that suicide occurs three times as frequently in those living with epilepsy compared to individuals without epilepsy. More recently, the Epilepsy Foundation (2020a) reported suicide deaths to be 2.6 to 5 times higher in individuals with epilepsy.

In addition, Attention Deficit / Hyperactivity Disorder (ADHD) is reported to be 12 to 39 percent more prevalent with individuals who are newly diagnosed and 70 percent of individuals who have refractory epilepsy (Rheims & Auvin, 2021). This is important to diagnose due to potential problems at school, work, and general psychosocial concerns. There is no reported specialized treatment of ADHD for those with epilepsy other than the usual treatment of ADHD with a focus for safety with those who have epilepsy (Rheims & Auvin, 2021).

Identifying and treating depression and/or anxiety for those living with epilepsy is important to maximize their quality of life. Use of reliable screening tools for depression, suicidal ideation, and anxiety are beneficial since these types of mental health problems can

take an emotional toll on individuals, marriages, and families. Examples of depression inventories include the Neurological Disorders and Depression Inventory in Epilepsy (NDDI-E), six statements in more than a dozen languages, the Beck Depression Inventory (BDI), and the Patient Health Questionnaire-9 (PHQ-9), or a shorter form, the PHQ-2 (de Oliveira et al., 2014; Kim et al., 2019; Sajatovic et al., 2019). Anxiety screening tools include use of the Generalized Anxiety Disorder (GAD-7) and Hospital Anxiety and Depression Scale-A (HADS-A) as being the most common (Wang et al., 2019). Psychotherapy, psychoeducation, family therapy, cognitive behavior therapy, anti-anxiety or antidepressants have been used successfully to assist individuals with epilepsy reduce depressive and anxiety symptoms (Epilepsy Foundation, 2020a). A support network is beneficial for individuals to interact about their circumstances and help to problem-solve obstacles and hardships.

Mobility Effects of Epilepsy

Mobility in one's community can be negatively impacted due to seizure activity, particularly in the area of driving. Each state has regulations about the eligibility of people to drive with medical conditions. For those living with epilepsy and seizures, there is usually a specific period of time for them to be seizure-free before they are legally allowed to drive. The specific regulations should be reviewed at the specific state's department of motor vehicles as well as online at the Epilepsy Foundation or https://www.epilepsy.com/driving-laws/2008761 (Epilepsy Foundation, 2020b).

Educational Effects of Epilepsy

Children who have epilepsy represent a unique population. They are at increased risk for poor self-esteem, problems at school with learning, grades, and school experiences, interaction with peers, behavioral issues, and a lack of social skills (Epilepsy Foundation, 2020a). Particular problems noted are attention and concentration, memory problems, and organization skills (Epilepsy Foundation, 2020a). This can be especially true for those with uncontrollable seizures. Some may have overall learning problems while others may have specific problems with learning (Epilepsy Foundation, 2020a).

Vocational Effects of Epilepsy

An additional effect of epilepsy with adults manifests in their ability to obtain and maintain employment. Epilepsy Foundation (2020b) reported that unemployment is greater in adults who have active epilepsy since 32.5% are unable to work. Also, approximately thirteen percent are limited in the type of work or the amount of work due to epilepsy (Epilepsy Foundation, 2020b; Kobau et al., 2014). Vocational counseling can be helpful to learn new job skills, get additional training, or find a job that the seizures would not increase risks. Developing a safety plan at work as well as obtaining accommodations at work would help to increase success in the workplace.

Resources for Epilepsy

The life care planner seeks to provide quality of care, enhance independence, and to identify current and future probable needs for those diagnosed with epilepsy (Weed, 1999).

Available resources for services and interventions would help to improve the lives of those living with epilepsy. The following listing of resources identifies practical resources for individuals with epilepsy and their families.

Resources for Self-Management and Mood Challenge

HOBSCOTCH (HOme Based Self Management and Cognitive Training Change Lives) is a program to help improve memory and attention for individuals with epilepsy. This program is designed for adult with seizures to help them to find strategies to manage and cope with memory problems. The program includes eight sessions by a memory coach that occur weekly and usually last 45 to 60 minutes. The sessions may be conducted by phone with at least one virtual or in-person session by use of a computer, tablet, or a webcam. The participants can have controlled or uncontrolled seizures. To learn more about this program, go to https://managingepilepsywell.org/publications-list?tag=HOBSCOTCH (Centers for Disease Control and Prevention, 2020a).

Project UPLIFT (Using Practice and Learning to Increase Favorable Thoughts) was initially developed and tested for those diagnosed with epilepsy at Emory University by Dr. Nancy Thompson as part of the Managing Epilepsy Well Network. It is an 8-week home program to work with adults who have epilepsy to improve their mental health. The program is provided through group telephone sessions that last an hour each. There are no more than seven participants involved in the group session at one time. The program uses cognitive-behavioral therapy approaches and mindfulness therapy to help to reduce mental health problems such as depression. Groups are facilitated by an UPLIFT trained facilitator and co-facilitated by a person with epilepsy. The groups are supervised by an UPLIFT trained mental health professional. Requirements to participate include a telephone conference line, participant manual, and CDs. The cost for the program varies depending on staffing and the group number. For additional information or to register for training, email mew.uplift@gmail.com. If a Spanish translation is needed, contact NYU School of Medicine research team or go to. https://managingepilepsywell.org/uplift (Centers for Disease Control and Prevention, 2020a).

PACES (Program for Active Consumer Engagement in Epilepsy Self-management) is to help improve self-management, community adjustment, and overall mental well being. It provides education about seizure types and treatments. It also encourages a healthy lifestyle and active participation in the community. PACES is provided through eight group sessions either in person or by phone. The facilitators of the group are a mental health professional and a person with epilepsy. The cost for PACES varies depending on staff and the number of participants. Topics covered during the group sessions include medical issues, dealing with stress and the blues, working with cognitive challenges, managing care, getting the most from the community, and effective communication, and well being. To learn more about the PACES program or to become a participant, send an email to the University of Washington http://depts.washington.edu/uwpaces/#contact or go to https://managingepilepsywell.org/paces (Centers for Disease Control and Prevention, 2020a).

MINDSET (Management Information Decision Support Epilepsy Tool) assists with self management, reduce seizures, and enhances quality of life within a diverse population of those living with epilepsy. This is a tablet-based or laptop platform aid for use at an outpatient clinic visit. It assists with collaboration between the healthcare provider and

the person with epilepsy. It includes a self assessment for the participant and an Action Plan that includes goals. For additional information about adopting this program or to find out its availability, contact the University of Arizona or the University of Texas. For more information, go to https://managingepilepsywell.org/mindset. The University of Arizona is partnering with the University of Texas and the Epilepsy Foundation in Texas to replicate MINDSET and enhance MINDSET to become MINDSET Plus. This new version is expected to help individualize recommendations and share findings (Centers for Disease Control and Prevention, 2020a).

TIME (Targeted Self-Management for Epilepsy and Mental Illness) helps to work with depression, stress, and other mental health issues as well as to decrease stigma. This program targets individuals with bipolar disorder, posttraumatic stress disorder, and schizophrenia who also have epilepsy. Psychoeducation and behavioral modeling with reinforcement is provided in a group format. The group sessions are provided in a 10 to 12 week period of time. The facilitators are a trained nurse educator and a person with epilepsy. The groups follow a written outline and each session lasts 60 to 90 minutes with a group of no more than ten participants. After the group sessions are complete, two telephone maintenance sessions would be scheduled with the nurse educator approximately two weeks apart from each other. Cost for this program depends on staffing, number of participants, and location. Costs are usually low for participants especially when they do not have other resources. Contact Martha.Sajatovic@UHhospitals.org or go to https://managingepilepsywell.org/time (Centers for Disease Control and Prevention, 2020a).

SMART (Self-Management for People with Epilepsy and a History of Negative Health Events). This program was created to improve health outcomes in people with epilepsy who are at high risk for poor health outcomes such as those who lack health insurance, veterans, and others who have disadvantages. A trained nurse and a person with epilepsy co-facilitate the group session. The initial group session is provided through teleconferencing. The group sessions are held over eight weeks with a written curriculum. The sessions usually last 60 to 90 minutes with no more than 12 adult group members. After the group sessions are completed, there are eight maintenance follow up telephone sessions with the nurse educator and facilitator with epilepsy. The maintenance sessions occur two weeks apart from each other. For more information, contact Martha.Sajatovic@UHhospitals.org or go to https://managingepilepsywell.org/time (Centers for Disease Control and Prevention, 2020a).

PEARLS (Program to Encourage Active, Rewarding Lives) is a program to help reduce depressive symptoms in adults and older adults as well as those who have epilepsy. There are currently more than 50 sites in 18 states that use PEARLS. The program includes six to eight in-home counseling sessions to help solve problems and become more socially and physically active. For implementation of a program, there are available online materials and training offered through the University of Washington Health Promotion Research Center (UW HPRC) in Seattle. Email is uwPEARLS@uw.edu. Their mailing address is PEARLS, UW Health Promotion Research Center, Hans Rosling Center for Population Health, 3980 15th Avenue NE, 4th Floor, UW Mailbox 351621, Seattle, WA 98195. Also, go to https://depts.washington.edu/hprc/programs-tools/pearls/ (Centers for Disease Control and Prevention, 2020a).

PAUSE (Personalized Internet Assisted Underserved Self-Management) is a tablet-based program that is currently under evaluation in Illinois. A research study is being con-

ducted to determine its significance for individuals who have refractory epilepsy. It is a tablet-based education program that helps individuals to plan and achieve self-management goals. There is one-on-one guidance with a PAUSE education facilitator. A healthcare provider will assign program content with an individualized pace to complete. A trained nurse or health educator would provide additional assistance and follow up via web conferencing. There is a 1.5 hour session at sign up then one session per week over 8 to 12 weeks. To learn more about this program, or to participate in the research study in Illinois, go to https://managingepilepsywell.org/pause (Centers for Disease Control and Prevention, 2020a).

YESS (Youth Epilepsy and Successful Self-Management Intervention) was a pilot study from 2018 to 2019 for web-based interventions for adolescents with epilepsy. This study was conducted at the University of Minnesota with ages 13 to 19. No findings have been published at the time (Centers for Disease Control and Prevention, 2020a).

Apps to Assist Living with Epilepsy

My Seizure Diary is an app created by The Epilepsy Foundation to monitor and to help manage seizures for individuals ages 4 and older. Use of the Chrome browser is recommended when using this application on a laptop . This app helps an individual record medications, side effects of medications, and track seizure activity over time. In addition, a Seizure Response Plan can be created and sent to family members and friends. This application helps with reminders to take medications, refill medications, and schedule appointments. It is a good tool to use when communicating with healthcare providers. It has iOS for iPhone, iPad, iPod touch, and Mac in addition to Android apps that are free. A complete listing of tools to use can be found on the web-based version at diary.epilepsy.com (Epilepsy Foundation, 2018).

HealthUnlocked Communities is a social network for health conditions, which links people with the same chronic conditions. It matches individuals with epilepsy. The user should use “epilepsy” and “seizures” when searching groups. This app helps those with epilepsy receive support and learn from others. It is free for iPhone, IPod touch, or Mac platform. The app is for ages 17 and older. A Communities app is a lite version for easier use with the HealthUnlocked Communities (Everything Unlocked, 2021).

Seizure Log is an app that helps people to manage their epilepsy by keeping records about their seizures and potential seizure triggers. The app has a Quick Capture button to time and record seizures as they happen or it can be used without the video function. This app is free for Android and iPhone, iPod touch, and Mac use. It is free for Android, iPhone, or Mac platform (Seizure Tracker, 2016).

Seizure First Aide is an app created by the Epilepsy Foundation of Minnesota. It provides first aid information for all types of seizures. It also has a timer since it is recommended to call 911 if a seizure lasts longer than five minutes. Videos of the five most common types of seizures are provided in videos. It is free on Android or iPhone, iPad, iPod touch, or Mac platform (Afixia, 2017).

Snug Safety is a daily check-in service to help those who live alone. Every morning, the person is notified at the selected time. The emergency contacts can be notified that the person has checked in, but this feature is also optional. If the person does not check in, emergency contacts would be alerted. There is a dispatch plan for a fee. This app is

free for iPhone use to alert emergency contacts. If a personal dispatcher is preferred, the fee is 9.99*permonthor*99 per year. With the dispatch plan, the individual can also call the dispatcher at any time of the day for help (PAVE Digital, 2021).

ICE Medical Standard allows one to place their emergency medical contact information on the smart phone's lock screen. The individual can add emergency phone contacts and medical information about their conditions. The app allow emergency personnel to power up the phone to see all of the information. The conditions can be color coded such as epilepsy could be coded red. This app is used in conjunction with the ICE Medical Standard ID Card as a backup. It is a free app for Android and iPhone (About the Kids Foundation, 2017).

Epilepsy Journal allows one to record seizure details and customize for each individual. There is visual images of data and tracking medications with reminders. This app helps to generate reports and view patterns to discuss or email to healthcare provider. For the iPhone, the app cost is $3.99. It is compatible with iPad, iPod Touch, and Mac (Cosic, 2016).

myChildren's is an app created from the Nationwide Children's Hospital that allows parents to track their children's needs. After entering the child's information, one can select the Epilepsy Toolkit, which allows the parents to record seizure details. There is also an area that the parent can add emergency treatment information. There are checklists and age-appropriate wellness tips for each child. This app is free for Android, iPhone, and Mac platform (Nationwide Children's Hospital, 2021).

SeizAlarm is an app to alert emergency contacts manually if the person thinks he or she is about to have one or the appt will alert automatically if an iPhone or Apple Watch detects a seizure-like motion. It does monitor elevated heart rate or repeated, abnormal movements. This feature can be disabled if a person is planning an activity that would elicit a false detection. There is no cost for the app, but there is a $14.99 fee per month for help request, $6.99 for alert service monthly or $149.99 per year for the subscription and $69.99 for yearly alert service (SeizAlarm, 2020).

EpiDiary is an app to help track epilepsy symptoms and has a Visual Medication Management (VMM) show actual pictures of medications since medications from different sources change color, size, and shape often. Individuals can record seizure details, medication side effects, mood, and other notes. It can also help track sleep. It is free on iPhone, iPod Touch, or Mac platform (Irody, 2021).

The Alert for Embrace Watch app pairs with the Embrace smartband and sends emergency contacts an automated SMS and phone call when it detects unusual movements that are associated with a seizure like a grand mal. It requires an iPhone with Bluetooth availability. It can send the person's GPS location if this option is chosen. The subscription costs are $28.99 for Alert Standard, $14.99 for Alert Lite, and $64.99 for Alert Plus. It is compatible with iPhone or iPod touch (Empatica, 2019).

Imspyre is an app that pairs with a user's Apple Watch or other compatible watch. The watch detects repetitive motion similar to a seizure and signals the individual's smartphone. This works with an iPhone or an Android to send texts or alerts to emergency contacts (SmartMonitor, 2021).

Resources for Educational Challenges

It is recommended that families, staff at schools, and healthcare providers collaborate to increase successes in the school setting and improve overall physical and emotional well-

being (Epilepsy Foundation, 2020a). This includes ongoing evaluation regarding a safety plan, identification and management of behavior issues, review of school extracurricular activities, accommodations, and enhancement of social interaction (Epilepsy Foundation, 2020a). Also, depending on the severity of the seizures, respite care may be needed to help families and caregivers. Programs such as affiliates of the EFA, The Arc, the Easter Seal Society, and the United Cerebral Palsy Association are resources to contact for additional information. Also, there may be local assistance through non-profit associations, churches, schools, and other community programs (Epilepsy Foundation, 2020a).

Seizure Action Plan (SAP) is a fillable document to record seizure information to include how long it lasts, how often, and what happens. It includes a checklist protocol of when child has a seizure at school. It also include a checklist for first aid and a checklist of when to call 911. Direction is also documented of when to use rescue therapy such as administering medication. There is an area for care after seizure, special instructions, healthcare contacts, and other information.. It also lists daily medications. https://www.epilepsy.com/sites/core/files/atoms/files/SCHOOL%20Seizure%20Action%20Plan%202020-April7_FILLABLE.pdf (Epilepsy Foundation, 2020a).

Additional Resources

Adolescent Health Transition Project

This resource focuses on teens and young adults with special healthcare needs, chronic illness, or disabilities. https://depts.washington.edu/healthtr/

advancingepilepsycare.com

Resources for parents, caregivers, and people with epilepsy. https://www.advancingepilepsycare.com

Advocates for Youth

This organization offers resource listings to talk with teen about growth and development and sexuality. https://www.advocatesforyouth.org

AEDpregnancyregistry.org

Call 1-888-233-2334 to enroll in the North American Antiepileptic Drug Pregnancy Registry. Massachusetts General Hospital, Harvard Medical School researchers are seeking be able to identify the safest AEDs for seizures during pregnancy. https://www.google.com/search?client=safar&rls=en&q=AEDpregnancyregistry&ie=UTF-8&oe=UTF-8

American Academy of Child and Adolescent Psychiatry

hey offer a series of fact sheets about various topics related to children's development and their well being. https://www.aacap.org/AACAP/Families_and_Youth/Facts_for_Families/Layout/FFF_Guide-01.aspx#letterE

American Epilepsy Society (AES)

The AED offers a membership to clinicians and researchers. There is a membership fee which includes ongoing education, newsletters, and a free subscription to Epilepsy Currents. https://www.aesnet.org/membership/aes-membership/member-benefits

Child Neurology Foundation

This resource provide a directory that includes epilepsy along with tools and resources for school, behavior, etc. https://www.childneurologyfoundation.org/?s=epilepsy&post_type=disorders

Cureepilepsy.org

This is a nongovernmental agency committed to fund research in epilepsy. Personal stories are presented from individuals with seizures from Citizens United for Research in Epilepsy (CURE). https://www.cureepilepsy.org

Epilepsy & Seizures 24/7 Helpline

Trained individuals answer questions about epilepsy and seizures. Call 1-800-332-1000 or Espanol 1-866-748-8008

Epilepsy.va.gov

Information on epilepsy and seizures specific for veterans. https://www.epilepsy.va.gov

Guardian Angels Medical Service Dogs

Central Florida Headquarters is located at 3251 NE 180th Ave., Williston, FL 32696. Their phone contact for general information is 800-398-6102 press #1. Dogs are trained to alert prior to seizures and alert for help. Applications and additional information can be found at https://www.medicalservicedogs.org/what-are-service-dogs/?gclid=Cj0KCQjwvO2IBhCzARIsALw3ASpUONj9jbVLPtFXIuOLPkaWkKSWn01ehiDvJ80HCljkI1Wnvd74K0aAvePEALw_wcB

healthfinder.gov

This is a federal website created by the US Department of Health and Human Services with other agencies. It is a resource to locate government and nonprofit health and human services information. https://health.gov/myhealthfinder

HEALTH Resource Center

This is an online clearing house for postsecondary education for individuals with disabilities. It has training sessions and workshops as well as provides fact sheets, directories. It also has a network of professionals in the area of disability issues. https://www.heath.gwu.edu/

MedlinePlus

Comprehensive health information from the National Institutes of Health and other sources.https://medlineplus.gov

NAEC-epilepsy.org

The National Association of Epilepsy Centers (NAEC) can help find an epilepsy specialist / center in a geographical location. https://www.naec-epilepsy.org/about-epilepsy-centers/find-an-epilepsy-center/

National Institute of Neurological Disorders and Stroke (NINDS)

NINDS is an agency of the US Department of Health and Human Services (HHS) and a component of the National Institutes of Health. Their focus is research but they also provide fact sheets about various conditions and offer public education. https://www.ninds.nih.gov/Disorders/All-Disorders/Epilepsy-Information-Page

National Institutes of Mental Health (NIMH) Children and Adolescents

This organization provides information about mental disorders such as depression, anxiety, learning disabilities, etc. Articles are directed toward children and teens with information about how parents can talk with their children about mental health issues. https://www.nimh.nih.gov/health/topics/child-and-adolescent-mental-health

The National Parenting Center

This organization provides information to parents about various topics from peer pressure, body image, drug abuse, and other topics. http://the-parenting-center.com

United States Office of Disability

This is a federal government website for information on disability programs and services. https://www.dol.gov/agencies/odep/program-areas/individuals/youth

Partnership to End Addiction

Focus is to prevent, treat, and help those to recovery. This is pertinent to teenagers as well as adults. https://drugfree.org

Sibling Leadership Network

This nonprofit seeks to provide sibings of individuals with disabilities support and information to advocate for their siblings. It also promotes issues that are close to the families. https://siblingleadership.org

Texting4control.com

This system helps participants age 13 and above with mobile phones to register to receive reminders via text messages about when to take medications. It also provides a motivational message. https://www.texting4control.com/welcome.php

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