Comfort Toys: Coping Tools for Children with an Epileptic Parent

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abstract

When a caregiver suffers from epilepsy, a child can often feel frightened, vulnerable, and alone whenever a seizure occurs. In my thesis project, I intend to help children negotiate this struggle with the use of therapeutic toys. Through play, children can navigate feelings that are often overlooked by adults. The visual appeal, simplicity, and materials used in their creation help facilitate comfort through sensory cues. By applying coping mechanisms to deal with stress caused by the passage of time, provide tactile comfort, and equip the child with tools to take action, their emotional needs are met. These toys address an overlooked need for children who consistently deal with the emotionally taxing occurrences that come with having an epileptic caregiver.
When I was young my mother had epilepsy. I remember her seizures always began with a heavy sigh, raising in pitch until her body fell against a hard surface. Pots and pans crashed and chairs tipped as mom’s body crumpled to the floor. When this happened at home I found a distraction – from toys to television – while the seizure ran its course. There was nothing further I could do but let it play out. The difficulties that arose when a seizure occurred in public while grocery shopping or at the mall were worse. I often felt as if I had little to no power to control what materialized around me. Strangers panicked, calling emergency services that were completely unnecessary. It was as if roles reversed, placing me as parent while parent became child. Yet, I was still perceived as child. As I sat by my Mom’s side waiting for the event to finish, time passed slowly. There were no distractions. I had nothing to aid me in these episodic situations. I consistently felt powerless. Mom never remembered what occurred, but I was keenly aware of the details.
The struggles children face when experiencing a caregiver's epilepsy are often neglected. During a seizure or grand mal event, children are unable to provide them with the ability to take action, offer reassurance, or feel empowered.
Through collaboration with public health practitioners, designers can help identify overlooked aspects encompassing a malady and address the deficiencies. In diagnostic methods both deductive and inductive reasoning are utilized to increase individual well-being. Deductive reasoning is strictly fact based and uses knowledge already gained to reach final conclusions. Inductive reasoning uses existing knowledge to find patterns within a set of data and suggest outcomes from those patterns. In design practice, an abductive thinking process is additionally applied in discovering solutions. Abductive thinking brings new data into play by experimentation. All possibilities are explored to locate connections between parts of a problem. By taking this abductive or experimental based methodology into the field of medicine, new links and solutions help solve health-related issues.
Seizures cannot fit into one realm of classification and have a wide spectrum of variability. Like a personality, a seizure is unique for each individual. Additionally, seizures and their symptoms change throughout the life of the epileptic. Soundarya Gowda, Doctor of Neurology at Virginia Commonwealth University Medical Center speaks of two decisive moments to be aware of when a seizure occurs. First, the duration of the seizure should last no longer than two minutes. If it is longer than two minutes, an emergency response team should be notified. Second, following the end of the seizure, a patient should respond after three minutes. Once again, if the response goes past this duration, emergency measures should be taken.
One problem the child will face is coping with the passage of time from the moment a seizure occurs to its end. When John Maeda was a professor at the MIT Media Lab, he wrote the book *The Laws of Simplicity*. In it, Maeda details how simplicity aids us in maintaining stability in our lives. One law he details is Time. He states, “Savings in time feel like simplicity.” He goes on to explain how the task of waiting leads to frustration. He cites research done by Apple Computer where subjects were asked to complete an on-screen task that involved a large amount of computer processing time. Those who had a progress bar displayed on screen perceived the event transpiring more quickly than those who did not. The visual cues within this progress bar helped to ease the passage of time, giving reassurance to the individuals. In my work I use this element to help the child through the duration of a caregiver’s seizure.
Creating a tie between a child and a toy provides additional mental support beyond its basic functionality. Donald Norman, noted author and Director of The Design Lab at University of California, San Diego, writes about this connection in his book, _Emotional Design_. Norman addresses three aspects of product design: visceral, behavioral, and reflective. Visceral describes the surface level of appearances and general aesthetics. Behavioral deals with the fun and pleasure in using the designed object. Reflective "considers the rationalization and intellectualization of a product." He writes, "Our attachment is really not to the thing, it is to the relationship, to the meaning and feelings the thing represents." Combining these three elements will provide an end outcome that fosters an emotional bond between object and owner.

Toys can act as empathizers offering a powerful solution to aid children through many burdensome times. Dutch designer, Twan Verndonck explores methods of providing reassurance in his Boezel project. Produced in 2001, these 17 toys "encourage sensory exploration and reduce anxiety." Verndonck utilizes materials that are sense-specific, "heating pads, mirrors, sound, scent, and durable textiles with different tactile properties." By making his Boezel creatures abstract, the child is prompted to use their imagination to create the story of the object. "Using tactility to find relief from tension and worry provides further paths of discovery within my work.

Shadow Buddies are dolls that have various maladies. Marty Postlethwait was inspired to create a doll for her son, Miles, who was born with multiple congenital birth defects. Miles had requested “a friend like me,” after having undergone 30 operations. Oncology Buddy has a chest catheter, shared by patients who are undergoing chemotherapy. Diabetic Buddy comes with insulin and syringe, while Breast Cancer Buddy has a right or left mastectomy scar to help a mother demonstrate to her child what is happening. In addition, breast cancer patients use the doll to “cushion their hypersensitive skin by placing it against the scar when they’re wearing a car seatbelt.”

2. The Laws of Simplicity, pg. 11, 17–26
3. Emotional Design, pg. 5
4. Ibid, pg. 6
5. Ibid, pg. 44
7. Ibid, pg. 234
process
A portion of my process was spent recalling memories during the years of my mother’s epilepsy. This small book explores a connection with my home, the objects within it and how these were part of my impression of that period of time. My home was a safe place away from public eyes. However, it was not safe from the ever-present anxiety.

For an assignment in the Visual Communications Graduate Seminar with Sandy Wheeler exploring “place”, I researched special areas designated by children. This ranged from their homes to the play shelters and dens they create for themselves. I considered my childhood home and began to document its various parts.

I recalled the aloe plant and its role in helping heal cuts and bruises. I remembered my mother sitting on the stout coffee table doing automatic, robot-like movements while she recovered from a seizure. I also recollected the crashing of pots and pans I’d hear coming from the kitchen.

Taking the viewer through this house from my perspective, I translated a few of the mundane items such as the front door, couch, and television into icons. Icons worked best to communicate the simplicity of these objects. Because of the paper stock and it’s tooth, the printer produced hazy edges where I expected crisp vector ones. This fit well with the notion of memory.
In Mervyn J. Eadie’s book, *A Disease Once Sacred* I came across a story that inspired the following study. He speaks of an individual who, when feeling a seizure coming on, would try to escape from public view. Hiding underneath a blanket or temporary shelter relieved him from having to navigate any public misunderstanding.9

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9. *Disease Once Sacred*, pg. 22
In the Visual Communications Graduate Seminar with Sandy Wheeler, I explored this shelter concept from the Icons of Home which resulted in a final book that doubled as a miniature shelter. In this book, I recalled the places I retreated to as a child: a blanket covering a bouncy horse toy, the nearby foothills of my Utah home, and thickets of trees. I went to these places to decompress and found relief.
I considered the shapes of shelters from my past associated with comfort—the organic form of the bouncy horse, rolling foothills, and tree configurations. By researching existing precedents such as collapsible dens for the homeless and emergency tents for shelter after natural disasters, I found inspiration. My concept was to provide a small portable shelter, easy for a child to deploy and carry around in public inconspicuously. I designed it to offer comfort when an epileptic seizure took place in public, in a similar manner as my childhood shelters.
When my mother had a seizure in a public place, I needed to shelter her from onlookers and I needed a voice to inform them of the situation. Returning to my places of childhood refuge I chose the tree which connotes strength and shelter. The tree became a backpack for the child to carry.

I began to design the tree backpack with familiar cartoon characteristics: large eyes, smiling mouth, and playful eyebrows. I was encouraged to go beyond the familiar by Jamie Mahoney and John Malinoski with the face treatment and make it my own. I began by researching tree forms, bark patterns and leaf shapes. I then photographed trees around campus and traced them to find faces in the bark patterns. My selection is based on the vulnerable look that this particular character offered.
To construct the backpack prototype, I selected cloth that best offered tactile comfort for a child. My 3-year-old son has a material called "minky" in his favorite blanket that he must have when going to bed. I used this and other soothing materials in the final construction of the toy.
Thank you for your concern.

Ask me before you call.

The worst thing you can do is panic.

This event is brought to you by epilepsy.

Epilepsy happens regularly.

Shield from overcautious adults.

Worried? Don’t be, it’s epilepsy.

My mom has epilepsy.

This is part of the routine.

Please
Relax

Situation in control.

POWERING UP.

Situation handled.

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This inconspicuous backpack and blanket provide children with an ability to take action when a seizure occurs in public. It additionally offers tactile comfort that can soothe the anxiety during this vulnerable moment. These simple objects and action address the anxiety, giving voice and empowerment to the child within this situation.

Don’t worry it’s only epilepsy

The phrase don’t worry it’s only epilepsy, was a final suggestion by John Mahoney, former copywriter for The Martin Agency, Richmond, Virginia. I chose it because of the simple, reassuring voice. By informing concerned onlookers that this event is somewhat normal, a child is perceived as an authority over the transpiring occurrence. The phrase facilitates a conversation between onlooker and child.
don’t worry
it’s only
epilepsy
In one of my first attempts to create a toy, I acquired a block of basswood. With no particular shape in mind, I began whittling the block. After cutting out too much from the top and bottom ends, a distinctive shape emerged. I carved a minimal face using a “U” shape to delineate eyes and a nose. Shaping the reverse side to come to a point caused the character to roll when placed on its back. This form became a rudimentary toy to help explain to a child the transformation that takes place during an epileptic seizure. When pushed, this totem was intended to roll over on its own to the reverse side. The reverse side displays a stylized blank stare, a characteristic I recalled when my mom was experiencing a seizure.

My initial endeavor to carve a character that rolled 180 degrees every time came up short. The rotation occurred, but inconsistently. In order for this object to be successful this flip needs to work every time. Further exploration is needed to recreate a form that more consistently represents the way the body collapses in a Complex Partial epileptic seizure.10

10. A Complex Partial epileptic seizure consists of three parts. The first is an aura or warning period where a sufferer becomes aware of an impending seizure. This is followed by an absence seizure, which can last another minute or two, when the individual may collapse and experience spasms or slight jerking. The final portion causes automatisms, or repetitive movements, that can be gestural or verbal.
Thinking of objects that fall then rise, a bowling pin came to mind. Using this shape, I carved a character from basswood. I noticed by clutching the shape it fit very comfortably in my hand, enabling me to massage the smooth neck of the character with a thumb. This repetitive motion reminded me of a similar object called a worry stone. The divot in this small stone is rubbed during anxious moments. This motion releases endorphins, easing tension.11 I shifted my focus from an object that teaches to an object that soothes - from an object that falls and rises to an object that fits in a child’s hand.

In exploring surface, I tried white automotive paint with a layer of clear coat. The sheen encouraged touch but the rough surface obstructed a positive tactile experience. In my research on color I came across electric guitar marbling, where artisans dip a guitar body into a vat of water with enamel paint suspended on the surface. Attempting the method, I dipped the objects into a swirl of blue and yellow enamel paint. I could not get the paint to stick to the primed wood. Gobs of paint dripped down the surface while drying, causing an ugly and unacceptable outcome. Finally determining that the original wood pattern was a beautiful visual and tactile experience, I chose to abandon my color studies.

My initial method of creating these objects was through the slow and tedious task of whittling. To speed up the process I began working on the lathe. However, the symmetry the lathe produced lost the charm the whittled versions held. The handmade imperfection added a level of individuality missing from the lathe versions.
Exploring wood varieties to create these objects I discovered olivewood (Olea europaea) and rosewood (Dalbergia oliveri). These two woods absorb oils from our hands. The more the object is used, the smoother it gets. Additionally, the tactile experience between the lightweight basswood and the more substantial rosewood is significantly different. Basswood felt light and of less value while olivewood and rosewood felt sturdy and precious. By working with higher quality material the tactile experience became notably stronger.
Considering the long wait I endured during my mother’s epileptic episodes, I created a character that would provide a visual cue to work as a progress bar. By adding adhesive vinyl eyes an hourglass becomes a companion where the time is perceived as passing quicker. The eyes communicate two states: one aware and happy, the other static and staring. When the blank side empties sand into the happy side, a child can anticipate the length of time a seizure takes. Seeing the happy side drain into the blank star side however, becomes a problem. This object only effectively works one way with the sand pouring from the static to the happy and makes no sense the other way around. This led to further iterations dealing with time.
In my exploration with the sand timer, the duration of time was based on a vague memory of how long I believed my mother’s seizures lasted. I thought they lasted for almost 30 minutes. After further research I discovered this time frame was incorrect. The type of epilepsy my mother had generally lasted about 15 minutes. This new design counts down from that period of time.

With the aid of Jason Pascoe, an undergraduate student in VCU’s Sculpture and Extended Media Department, I constructed a simple box by cutting out basic notched joints and fitting each side to the circumference of an inner timer. A small shim was placed at the 15-minute mark to prevent advancement past that point.
When twisted 90 degrees, the timer begins. The box misaligns and returns back to its original form after 15 minutes. This was a translation of the altered persona that takes over during a seizure. I added color to the box to reinforce this misalignment by creating contrast. Additionally, I considered an image of the child on the top portion of the box with the caregiver’s image placed below. Another option was an application of the parent’s face split between these same planes.

Continuing with this timer concept, I explored scavenged wood from a thicket of trees. After cutting this wood to size, the grain bore striking patterns. My initial intent was to show the same misalignment of the grain while adding a bold color stripe through the piece of wood. The grain and stripe would then realign over the course of 15 minutes. This approach was abandoned after significant distortion occurred when the wood dried. In tandem with the original box idea, I felt like this object appealed to me as an adult, but lacked the visceral and behavioral aspects that would appeal to a child.
Another exploration was a plaster mold that Jason Pascoe created. The exterior texture worked similarly to what I expected from the grain of the scavenged wood. The round object offered little visual distortion outside of the subtle change in texture. In addition, the thick plaster muffled the sound of the ticking timer. By having little sensory stimulation the concept of a progress bar was non-existent. The importance of both of these sensory outputs needed to be part of my further explorations.
The basic forms in the toys of Joaquin Torres Garcia, Libuse Niklova, Ladislav Sutnar and Japanese toy craftsmen have provided insight into my own form creation for this character-based timer. Beginning with form exploration, I drew many shapes working to maintain a similar simplicity. By elongating circles, skewing rectangles, and softening triangles I intuitively searched for something to resonate a feeling of endearment.
I visited the Studio Furniture/Wood Program’s woodworking facilities in the Department of Craft/Material Studies at VCU. Looking for insight into wood working I was struck by the use of dark walnut paired against a light maple in a tabletop. Within the same object, each portrayed two contrasting sides. Similarly, my mother had two sides to her persona, the non-episodic side and the episodic side. These two woods combined began to express this idea.
I was attracted to a simplified “A” shape I had sketched and determined to create a character from it. I glued several pieces of douglas-fir together to create a block that I could carve on the lathe. However, I was advised by the sculpture shop manager not to commence with this particular block. He told me that there was a certain way to glue correctly for cutting on the lathe. My next option was to use the band saw to achieve the shape. Tilting the table of the saw to its maximum 30 degree angle allowed for a dynamic shape. This new shape varied greatly from the cylindrical shape I would have been able to produce with the lathe.
The head was created by trimming two inches from the top. Both head and body had cavities cut out to hold a timer. As the form emerged, I realized I didn’t need as much space for the timer as I had allowed from my drawings. Additionally, this object was too large for a child to carry around in order to be ready for a seizure. This object as a plaything was unrealistic. I needed to create something smaller.
Art installations that double as shelters

Monika Mudder
Chair (Idea)
I returned to the lathe and band saw in pursuit of this smaller size. I revisited some shape studies I did in my sketch book. These shapes were relatively easy to recreate and I discovered when they were combined, formed characters. I designated head, torso, and leg shapes that could be interchangeable with the others. I began with straight cuts using the band saw, creating a more angular character. Using the lathe, I then created a cylindrical based character by combining maple and walnut.
After a discussion with my secondary advisor, John Malinoski, I discovered that in combining these shapes a child could create their own parent. Using the interchangeability as an educational tool a conversation is facilitated between parent and child. With this tool, the parent can show their child that, sometimes, mom or dad can fall apart, but will come back together again.
By combining what I learned from the "A" shaped character and the smaller modular forms I discovered a way to create a more practical toy. I found in these two objects another opportunity to incorporate the knowledge gained from my conversation with Dr. Gowda. I created sections for each of the portions within an epileptic episode (see page 15). A timer turns the head of the character clockwise, delineating the two-minute seizure. Another timer turns the legs of the character counter-clockwise, indicating the full seizure including the automatisms. By turning the head and legs at the same time, the full process takes five minutes. When both portions complete their rotations the child should attempt to get a response from the adult. This response can be as simple as eye contact when the parent’s name is called. If either of these episodes extend beyond these time periods, emergency services need to be called. Like Maeda’s progress bar this character offers the child a practical toy that helps through the duration of a seizure.
The worry wood, timer character, and tree backpack have yet to be tested on an audience for whom they are intended. This testing will be critical in order to validate my conclusions that anxiety can be soothed, that empowerment can be given, and the passage of time can be eased through the tools of toys. This research will be my next step. I will be visiting with neurologists in my next locale to begin the testing process. I also will be using online forums such as the epilepsy foundation, to discuss this research with the public. Additionally, I have further ideas that I would like to see realized. The first is an object that falls and rises with the push of a button, helping the caregiver to explain epilepsy. Others teach through picture books and board games. I also see a continuation of ideas stemming from objects that I have created over this past year. I found the continuous generative process to be a valuable method in the creation of these toys, and will continue to practice it. Additionally, I see higher education as an ideal realm to move forward in the development of this generative, cross-disciplinary work. This application will be implemented in my pedagogy by facilitating life experiences for students with visits to community centers, shelters, and foundations.

The experiences within will provide insight into perspectives that help build empathy that we as designers need to address problems effectively.

The use of the abductive design to address physical, mental, and emotional needs for the benefit of those around us is design at its best. At the opening night of my thesis show I visited with individuals who told me stories of family members who had epilepsy. One particular visitor told me she was an epileptic and very much identified with the overlooked child. I was further encouraged in making this connection, discussing the outcomes to someone who similarly understood the need. The conversations that these objects brought out reinforced to me their necessity in these children’s lives. I will continue to explore methods and processes to help bring comfort to those who experience epilepsy through their caregiver.

Through my experience at VCU, I found passion and joy in my work that was missing for the past ten years in my professional career. I discovered things about my work I enjoyed — it’s concept driven, engaging, intellectually-challenging and altruistic. I wasn’t fully able to explore these things until I came to graduate school. My interests became apparent as this program emphasizes methods of self discovery.

The chance to investigate outcomes that expand beyond the touch of the mouse, keyboard and glow of the screen enlivened me further. In my undergraduate degree, hard walls had been put up to define Graphic Design’s boundaries; this type of view does a disservice to the discipline. Experimenting with different processes and media can bring about solutions that myopic views cannot: Exploring tactility, materiality and physically does not diminish my ability as a graphic designer, it further enhances it.

In this expanded view I’ve been able to further my skills in woodworking and textiles. I was also able to work with a network of individuals from different disciplines that informed my process. Without the knowledge of those experts from woodworking, fashion, and sculpture, I would not have achieved the final results I did. Had I relied solely on myself to create solutions for this thesis project, my output would not have been as strong.

Crossing disciplines has expanded my knowledge and created engaging solutions.

evaluation
A study of materials through history, cognitive development and age group needs provided insight into how children act with different varieties of playthings. Using this information I worked toward creating toys with more challenge and engagement.


The perspectives in this first chapter reinforced my gravitation toward the use of wood in many of the toys I created.


Having always been struck by this duo’s work, I wanted to fashion objects as effortless and as engaging. Their simple forms and basic features bear a distinction that I wish to display in my own work.


Provides insight into a perspective of how the public has historically reacted to epilepsy. It also offered a look into behaviors of those with epilepsy and how they attempted to manage episodes. One story details an account of how an individual sensing an approaching attack who would find shelter or a covering to be hidden from view.


The author presents a look into how children work through difficult situations with the use of toys in a therapy setting. The ability for children to create their own objects offers an outcome that encouraged the manifestation of deep-seated frustration or worry. This manifestation is addressed through communication with the Therapist.


Researching the history of the toys in the past century gave insight into differing styles and applications that many artists employed in their toy creation. Lissie Nikola, Lisladeh Suhvar and Bruno Munner are detailed. The shapes they used in their toys inspired similar forms in my work. Similarly, Tuvan Verdonck’s Boezel project is mentioned, informing my process in the investigation of the tactility and comfort of touch in the tree backpack.


Lachterden provides further understanding in variously aged children’s comprehension of what was occurring when their parent had a seizure. This was one of the very few sources I found that discussed parental epilepsy’s effect on their offspring.


In understanding the mental anguish of waiting, Maeda explains reasoning and methods behind easing the passage of time. If the perception of the passing of time seems to be shorter, the endurance is less demanding. This informed my process in the creation of timer based explorations.


An in-depth look into three categories important in creating products that form bonds between it and the user. The three aspects of product design, visceral, behavioral, and reflective, aided my understanding of how to create objects that connect with the user on a deeper emotional level.


In the investigation of the tree backpack I explored shelters children made during play. The book details how these provided a brief seclusion and a sense of protection. This connection was important in investigating a shelter or covering that a child could supply for their caregiver in need.


Looking for insight into the history of toys, I researched wooden Swedish toys. Pulling from the production of these forms, I explored methods that I could execute myself. Many of the companies mentioned still make wood toys today—their forms and color treatments offered insight into the objects I created.


Ram’s simplicity influenced the way I began to look at shapes in character creation. Everything from his knobs to the product’s shape yielded ingenuity into the forms I fashioned.


Researching other cultures and the toys they created led me to the Japanese toy designers. Mediums for the creation of the toys varied according to the location of the artisan and what materials were available. The smooth lath work of Kokeshi Dolls inspired my use of the lathe.


Taking a deeper look into the manifestations of my mother’s epilepsy, I found many similarities between her symptoms and those found in Complex Partial Seizures. Using this discovery I set out to determine the duration of these seizures. This was the basis from which my timed explorations stemmed.

“Toys for a Brighter Future.” COLORS, no. 29 (January 1, 1999).

This issue devoted to a theme introduced me to toys that offered empathy, especially Shadow Buddies, dolls that share the same malady as the child. They demonstrate that something simple can deliver a powerful solution to work through challenging situations.
To my wife, Natalie for being the wonderful person you are. In my first semester I was told by a visiting artist that you must be something special to go through grad school vicariously through a spouse. I know that is true. Despite all my long hours away you provided unyielding support and encouragement. I love you more than words can express.

To my incredible son, Abel who runs creative circles around his Dad. You continue to inspire me everyday. The VCU Graphic Design department will dearly miss you, probably more than they’ll miss your Dad.

To my darling daughter, Zola, who will always be a Richmond native. Your laugh that exposes your freshly budding vampire teeth brightens my day. You may not remember this part of your life, but it will be one your Dad won’t forget.

To Jamie Mahoney for the hours and hours spent in transit from Henrico County to the Pollak building. I will miss our political discussions and teaching advice interspersed with a little bit of thesis talk. You have challenged me immensely. In the moment I quietly protested, but now am grateful for having persisted, making my outlook that much clearer.

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