

Living with Rodger

By Emilee Cope

Spring 2021 IN THIS EDITION:

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On August 25th, 2015, Riley Marshall was just nine years old when she was diagnosed with Inoperable Pilocytic Astrocytoma, a type of brain tumor that causes many side effects - the most persistent being chronic migraines which can lead to month long hospital visits.

Since the age of two, Riley had been practicing ballet and once she was old enough, she began to enter competitions; she even went as far to win a title for her dance company. However, while attending a national dance competition in July of 2015, Riley began to experience migraines and headaches on a daily basis.

"One was so bad, I had to pull her out of her dance class," stated Dawn Marshall, Riley's mother, "that's what got the ball rolling that there could be something wrong."

In addition to the persistent headaches, Riley's vision had increasingly worsened to the point where she saw only blackness out of her right eye. Riley's eye doctor referred her to an eye specialist who ordered numerous tests and from this they determined that what Riley was suffering from was, in fact, a brain tumor. Riley named her tumor "Rodger".

Throughout her diagnosis and treatment, Riley stated her family has "always been open and honest. As soon as my parents found out, I found out, and later when my sister got home from school, she found out" and as a family they've "dealt with it together."



Handling the diagnosis as a family and allowing Riley to make her own choices is something Dawn has emphasized throughout Riley's journey. "Some parents say 'this is what we're going to do, we're not even going to discuss it,' however, since day one Riley has had a voice in everything."

Furthermore, Riley stated "I feel like that's often a mistake parents make" and that, "I think parents should let their child have a choice because it is their body, and it's what's happening to them so they should get a say."

While such a diagnosis would be hard to accept at any age, "Riley has been a champ through it all," Dawn stated. "The day she had her brain biopsy, the very next morning, she was at the windowsill doing ballet," explained Dawn, "the doctors, they were all like, 'I can't believe she's up out of bed, and that she hasn't asked for any pain medicine'."

While unfortunately Riley is no longer able to practice ballet, her diagnosis hasn't stopped her from pursuing her other passions in life, including her love for school and reading. "I'm very into school and I like to look at colleges" Riley said, "I already know what I want to do, I want to major in Broadcast Journalism and I want to be a reporter on the news."

When Riley was asked how her diagnosis has affected her personal life aside from dance, Riley explained "People tend to treat you differently when they find out something like this; they are very standoffish and cautious," she continued by

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8422 Bellona Lane, Suite 102
Towson, MD 21204
p: 410.560.1770 • f: 410.560.1775
coolkidscampaign.org

Editor-In-Chief:
Reneé Wooding

Managing Editor:
Terry Lombardi-Nalls

Design:
Linda Ports

COOL KIDS CAMPAIGN STAFF:

Chris Federico
President & Founder

Janet Robinson
Director of Operations

Reneé Wooding
Managing Director

Melissa Scott
Managing Director, Charlotte

Terry Lombardi-Nalls
Community Relations Coordinator

Kylie Fargo
Community Relations
Coordinator, Charlotte

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ABOUT THIS ISSUE...

The Spring edition of Connection focuses on teen (and “almost teen”) patients and survivors. The emotional issues related to a diagnosis can be complicated for teens due to all the other changes they are experiencing. In addition, their condition can make them more dependent on parents at a time when they want to be more independent. This issue shares the stories from those facing these challenges (and doing it during a pandemic!). We’ve also included some ideas that can help lift teens’ spirits – including how helping other brings joy to teens. And you can get your teens busy in the kitchen with the help of the yummy recipes provided by our friends at Weis Markets. We’ll even explore how video games can be helpful in managing these stressful times.

By the way – Cool Kids now has a private gaming server with games like Fortnite and Minecraft, as well as more traditional games like chess, checkers, Uno and backgammon.. It’s a great way for pediatric cancer patients and survivors to connect and have fun. Contact me at renee@coolkidscampaign.org if you want to get in on the fun.

HOW GIVING BACK ARTFULLY CAN GIVE YOUR TEEN A BOOST

This article was originally published by International Arts + Mind Lab - The Center for Applied Neuroaesthetics

The teen years. They’re a rollercoaster of changes that come fast and furious as the brain and body struggles to adapt to a new world order. Sound familiar? Even for adults, the pandemic can feel like an unwelcome callback to our adolescence.

Parents often gripe about their teenager’s mood swings and sometimes questionable judgment, chalking up any unpleasantness to raging hormones. With stay-at-home orders in place, the whole family may be feeling these teenage ups and downs more acutely. That’s because the teenage brain is not meant for a life of confinement. Cut off from their typical sources of joy and entertainment, teens may feel especially stifled right now.

The good news is, there are ways to meet teens’ developmental urges that are safer for the whole community. Though they are stereotypically ridiculed for their self-absorption, it turns out that teens have a fundamental need to give back. And there are many people in need of a helping hand right now.

WHY DOING GOOD IS GREAT FOR YOUR TEEN

During the teen years, those hormonal changes like increases in dopamine make our brain circuitry more responsive to rewards. Teenagers are naturally wired to seek out rewards that elicit pleasurable feelings or cause them to

learn, like socializing with friends, taking risks and trying new things.

The brain’s reward system also lights up when helping others. This is largely due to humans being social creatures. Because teens tend to have growing social circles, it’s easier for them to find causes to back. This allows them to double down on the joy of making a difference in their communities while feeling a sense of belonging and identity.

It turns out that helping others not only feels good but actually is good for you. Teens who give back can enjoy benefits to their physical and emotional health. In one study, tenth-grade students who volunteered weekly with elementary school students had lower cardiovascular risk (cholesterol and BMI) than those who didn’t volunteer. The more they volunteered, the lower their risk. In another study, teens—particularly those who were experiencing higher levels of depression—reported being in a better mood on days they were giving back to others.

In perhaps the best news for parents, helping the family out actually makes adolescents happy. These contributions—like caring for siblings or helping to cook, clean or run errands—can both promote and fulfill key

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Teens in the Kitchen

Taylor Simpson, MS, RDN, LDN
Registered Dietitian at Weis Markets
tbsimpson@weismarkets.com

There are a variety of benefits to inviting your teen into the kitchen to get hands on as you prepare a meal together. First, it can be a great bonding experience, something to do together that can have a lasting impact. You can also share with your teen valuable cooking skills that will last a lifetime. Establishing cooking skills early on can help encourage a confident chef as they move into adulthood. Having your teen prepare a recipe is also a great way to encourage them to try new foods as they may be more likely to try a food if they prepared it. You can also allow your teen to get creative and make suitable changes to recipes so they can learn what flavors pair together.

Depending on your teens past experiences in the kitchen, you can start by teaching them how to read a recipe and then allowing them to watch you do a step of the recipe before they try. Your teen can get involved in measuring, cooking on the stovetop, and even basic knife skills. Once your teen is comfortable holding and maneuvering a chef knife, they can try to master more intricate knife skills. Check out the Cool Kids YouTube Channel to find a recent video that showcases some simple knife skills. Now lets look at some common words you may see in a recipe. Understanding a recipe is the first step for your teen to make a successful dish. After reviewing them, try out some of them in the recipe below!

Dice- a method of preparation that involves using a knife to transform whole produce into small square pieces

Mince- a method of preparation that involves using a knife to transform whole produce, such as garlic, into the smallest size you can manage

Pinch- a measurement that is based off 1/16 teaspoon; the amount you can pinch between two fingers

Boil- heating a pot over high heat until bubbles are constantly rising to the top of the pot

Simmer- heating a pot of water to a boil and then reduce heat so there are no bubbles

Zest- using a zester on the outside colored peel of a fruit such as a lemon, lime, or orange. Be sure to rinse your fruit before zesting.

CONFETTI FRUIT SALSA

INGREDIENTS:

- | | |
|--|------------------------------|
| 2 ripe mangos, peeled, pitted, and diced | 1 teaspoon lime zest |
| 1 Granny Smith Apple, diced | Juice of one lime |
| 1 cup strawberries, diced | 2 tablespoons sliced almonds |
| 2 kiwis, peeled and diced | cinnamon sugar pita chips |
| 2 tablespoons Weis Quality Honey | |

DIRECTIONS:

- In a medium bowl, whisk lime zest, juice and honey; add fruit and toss evenly to coat.
- Top with almonds and chill at least 1 hour; serve with pita chips.



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adolescent needs for autonomy, identity, and intimacy. Helping other people may also increase the likelihood that teens learn to show sympathy and empathy for others, marking their maturation toward young adulthood. It's more than an old saying: science shows that giving really is better than receiving.

HOW TO GET STARTED WITH ARTFUL ALTRUISM

There are many creative ways that teens can help others (and reap the benefits themselves) during the COVID-19 crisis.

FOR THEIR COMMUNITY

- Make cloth face masks to distribute to friends, neighbors and essential workers.
- Participate in the #SafeHands challenge on Instagram. Make a fun video to demonstrate handwashing skills.
- Write letters or make art for a local nursing home or senior center.
- Raise money for relief efforts. Make cards, artwork, jewelry, or other handcrafted items to sell virtually. Or organize virtual "thons" (walk, skate, bowl, swim, bike, rock, read, dance) of an activity that people can do and track individually. Anython and RallyUp are two online tools that can help you organize these.

FOR NEIGHBORS

- Spread cheer and positive messages in your neighborhood by creating sidewalk chalk art, painting kindness rocks, or organizing a teddy bear hunt.
- Create a Little Free Pantry in your neighborhood.
- Clean up a yard or plant flowers for an elderly neighbor.

FOR FAMILY & LOVED ONES

- Take your younger siblings on a virtual field trip.
- Cook dinner for the family.



KINDNESS ROCKS

PUZZLES AND GAMES

SPRING WORD SEARCH

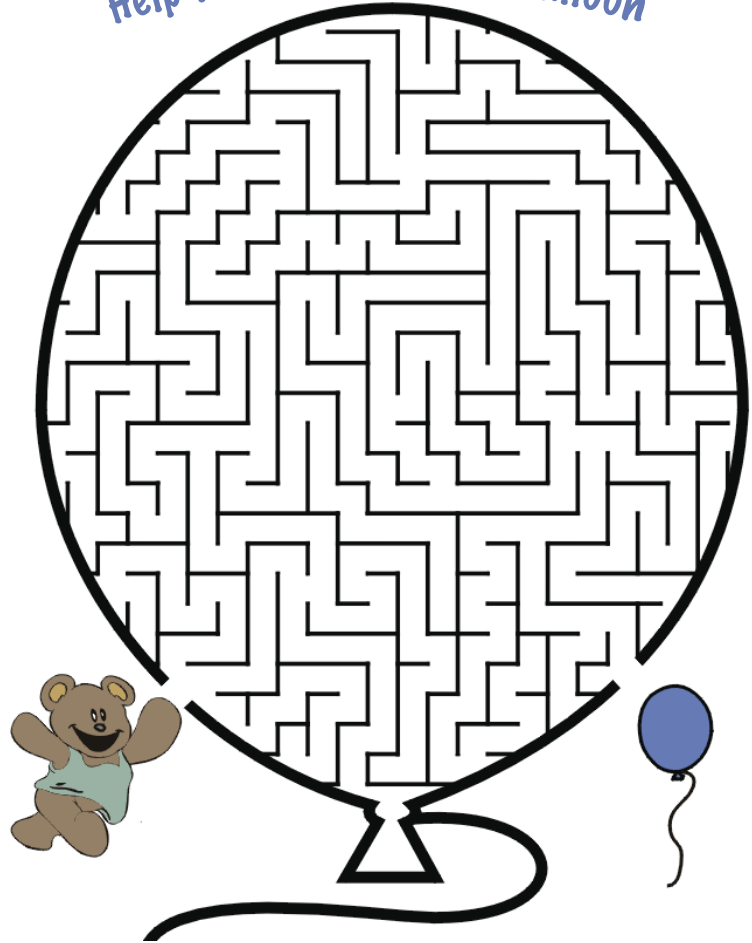
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BIRDS	CALF	GARDEN	LAMB	SNAIL
BLOSSOM	CATERPILLAR	GRASS	NATURE	SPRING
BUGS	CHICKS	HATCH	NEST	SPROUT
BUNNY	FLOWERS	INSECTS	RABBIT	TULIP
BUTTERFLY	FROG	LADYBUG	ROBIN	WORM



Help the bear catch his balloon



Fill in the blank squares so that each row, each column and each 3-by-3 block contain all of the digits 1 thru 9.

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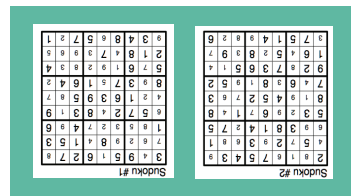
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ANSWERS













BRAIN THEASERS

I SPY SPRING CHALLENGE

Count how many of each picture you find. Write your answer down below in the boxes.



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FUN FACTS!

What are cicadas?

This May, billions of cicadas from Brood X are set to burst from the soil of the eastern United States after 17 years leading mysterious lives underground. When the soil about eight inches below the surface reaches 64 degrees this spring, cicadas will start to claw their way towards the light. They're expected to emerge by the billions across 14 states, with the epicenter in the District of Columbia, Maryland and Virginia.



CICADA

The Cicada is an insect that lives underground for 17 years!

It is the loudest insect in the world and can drown out the sound of a lawnmower.

The cicada has two drum-like chambers in its body called "timbals" that make the sound.

Though the cicada may look mean with its big, red eyes, it is harmless to everything but very small trees.

Color me green brown, and yellow, with red eyes!



10 INTERESTING FACTS ABOUT CICADAS!

- Cicadas are **harmless**. They do not bite or sting.
- Although many people think cicadas are part of the **locust family**, they are actually part of the **Hemiptera** species of insects.
- Canada has **20 Native Species** of cicadas. Most are found in **British Columbia** and **Southern Ontario**.
- Adults live for **4-6 weeks**, long enough to mate, lay eggs and avoid **predators**.
- Annual cicadas** are mostly found in **Australia**.
- Cicadas produce one of the **loudest sounds** known to man. Some species can reach **120 decibels!** (which is louder than a rock concert).
- Lawnmowers, power tools** and other loud noises attract cicadas.
- Females** lay eggs in twigs and branches of trees. When the eggs hatch, the **nymphs** jump to the ground and burrow in the soil.
- 'Periodical' Cicadas** live in the ground for **13-17** years and emerge in the billions. Once emerged, in some places they outnumber people **600 to 1!**
- Scientists believe Cicadas emerge in 13 and 17 cycles because they are **prime numbers**, making them difficult for **Predators** to keep track of.

COOL COLOR ME

Color By Number

blue = 1

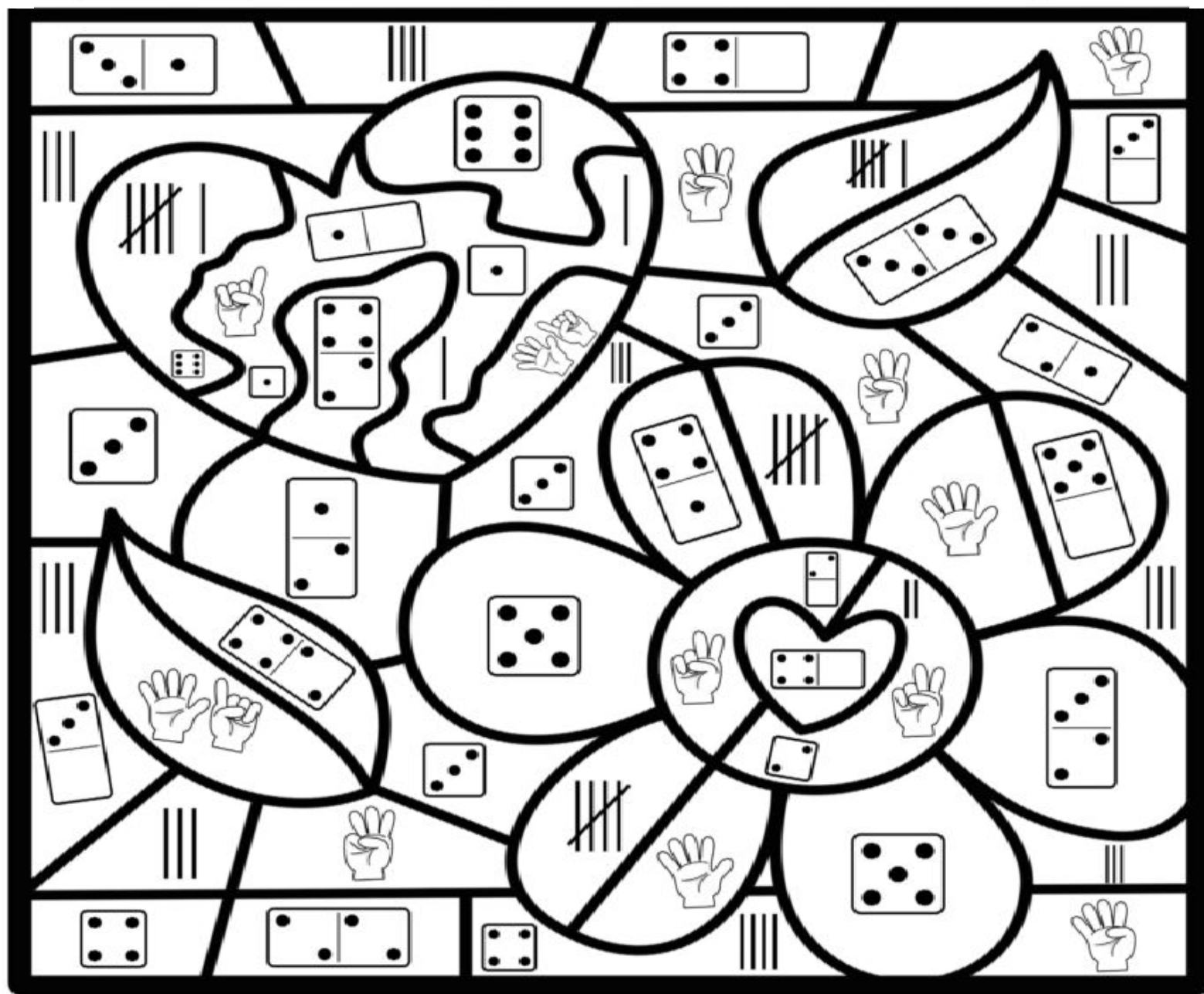
orange = 2

yellow = 3

pink = 4

purple = 5

green = 6



(continued from the cover, *Living with Rodger*)

stating, "My friend group did grow smaller. Some of them were weirded out by it, but I don't necessarily think that's a bad thing, you don't need friends like that."

Even though Riley's friend group did grow smaller, her sister Raegan was by her side the entire time. "It's important to be there for your siblings," Raegan stated.

Dawn went on to then say, "She's my hero for the way she handled it" and that "When Riley was sick, Raegan would go on and do her chores no questions asked and she still does take care of her sister to this day."

"The one thing that always sticks with me, is when she got the diagnosis. As a mother you're afraid to hear, 'why me?', but that's one thing that's never come out of her mouth." Dawn stated. "The only thing she said to me, and I'll never forget it, was 'Mom I know why God picked me, because he knows I'm strong, I can handle it and I'm going to change the world'."

When Dawn was asked what advice she has for parents who are experiencing a similar situation, she stated "The best advice I can give to parents is to talk to your kid, tell them the truth, don't keep anything from them, and you have to keep the faith."



Childhood Cancer During Extraordinary Times

By Ryan Fisher

A lot happened in 2020. In what now seems like a lifetime ago, 2020 started with some of the most devastating wildfires ever witnessed on the planet, where in Australia a record 47 million acres burned. Little did we know, those wildfires would be the beginning of the most unusual and difficult year of our lives so far. The fires were followed by other extraordinary occurrences such as nationwide protests over racial injustice, world-wide civil unrest, a frenzied election season, and let's not forget the once-in-a-century pandemic that swept the planet. 2020 was also the year that our daughter was diagnosed with cancer.

It is estimated that more than 15,000 children were diagnosed with some form of cancer during the year 2020, and our daughter was one of that number. In April our family had just begun to get accustomed to the idea of our new quarantine lifestyle. We were staying home and keeping ourselves isolated when our daughter started experiencing strange symptoms, complaining about sore ankles. We also noticed that she seemed to be bruising easily. But, she was an active and happy 12-year-old child and we assumed that the soreness and bruising were the result of being just that—a happy, healthy and active 12-year-old.

A couple of days into April, her pain had become unbearable and we reluctantly took her to the local emergency room. We knew that a visit to the ER would be an ordeal due to COVID-19 restrictions, but we felt like we didn't have much of a choice. We assumed they would check her out and tell us that she had a sprained ankle and that we would be on our way home in short time. I wasn't even allowed to go into the building with her and her mom, but was required to wait in the parking lot where I paced for a couple of hours. Finally, the call came from my wife inside. Ready to pack up and go home, I answered the phone and my wife said "The doctor here thinks she has leukemia..."

If you are reading this, you are likely a parent or family member of a child who has been diagnosed with cancer and you have already experienced this life shattering statement— "Your child has cancer." These words brought me to my knees right there in the parking lot of that hospital. I was in a dark and cold parking lot, separated from my family who were now being rushed into the back of an ambulance and off into a new existence.

Fast forward—our daughter has been in the pediatric ICU in another city and we have all been isolated from friends and family for nearly two weeks, all while the pandemic has really started to take hold and change the world outside the walls of the hospital. The closest children's cancer clinic is over 60 miles away from our rural North Carolina home, and we are starting to get an idea of just how this situation is going to absolutely consume every aspect of our lives for the next few years.

We also began to learn that a lot of the things that have been available to childhood cancer patients in years past are now locked up and off-limits due to the pandemic. Normally, children healthy enough to do so would be allowed to gather in play rooms to do arts and crafts and to play and just be around other kids who are going through the same thing. Now, those rooms were all locked up. The engaging programs that have been designed to help children through this horror had been put on hold. Not only was our daughter trying to learn how to cope with this new and very scary diagnosis and dealing with the isolation of the pandemic, she was isolated from other children altogether. This was going to be tough, but we didn't have any choice but to push on and struggle through it.

As the country drew inward and became more isolated, so did all the folks around us. People across the world were told to try and keep away from others (us cancer families even more so), and I began to understand that in this situation we would likely go it

alone. Long-time friends and family withdrew. Everyone was understandably worried about their own families. While we were learning how to manage our very unique new way of living, the rest of the world was also figuring out how to survive a pandemic. We quickly discovered what that meant was everyone else was going to be consumed with their own problems and worries. Everyone else withdrew into their own world and in to their own secluded existence, and our little universe quickly became just the three of us. We were going to have to do this on our own.

The pandemic got worse. And worse. And worse... and the whole outside world went kind of chaotic all while we were travelling to and from the clinic, 600 miles in the car each week, through the most difficult and painful parts of our daughter's treatment. While people were marching in the streets across the country, and while some of the bigger cities witnessed rioting and violence, we kept our heads down and kept pushing forward—back and forth to the clinic every day—doing what had to be done. I clearly remember watching live reports of rioting on the local news at night during the summer, and trying to map out in my mind the best route to the hospital in case our daughter spiked a fever. I worried that the city streets would be blocked or too dangerous to drive through and I wouldn't be able to get her to the hospital in time.

I watched as other parents posted to social media their grief for their own children and how hard the isolation was, how hard virtual school was, how much they missed sports and being with their friends. I would often read these things while sitting in the clinic next to my daughter who was getting a blood transfusion or having a chemo treatment while doing her school work, and I would think about what I would give to only have the worries of those other parents. All of the kids of the world had a hard 2020, but there is a hidden population of children whose biggest concern was not that they missed out on a year in school with their friends. There are thousands of children who spent 2020 not bored and tired of having to stay inside, but scared and fighting for their lives.

Our story, however, is not unique. There are thousands of families in our country who are going through these very same circumstances. Odds are that if you are reading this, you are a parent who is just now experiencing this new reality. It's terrifying, I know. I also know that every situation is different and that ours may be far less scary than yours may seem right now. What I have learned throughout the hardest year of our lives is that all of this is going to seem really, really hard—perhaps impossible—but what you will find is that all of you—everyone in your family—are a lot stronger than you think you are. People will say to you "I can't imagine what it must be like" and they are right. They really don't know just how hard it is. They will probably never know how tough your situation has been. But you will do everything that is necessary to help your child, no matter how hard it may seem at the time. You will find out just what you are capable of during this season of your life, and I bet you will be surprised to find out how strong and resilient you really are.

Hang in there, mom and dad. Know that no matter how isolated and trapped you may sometimes feel, you are not alone. Surviving everything that 2020 had to throw at us, then managing childhood cancer on top of it all seemed impossible at times. With the help and generosity of charities, the brilliant and loving and genius and wonderful medical staff at the clinic, and a whole lot of grace from God, we got through the hardest year ever.

No matter how out of control your life may feel or how alone you think you are, there are others out here just like you who know what you are going through. There are thousands of us and we've got your back.



How Video Games Can Be a Healthy Escape During Lockdown



Written and reported by IAM Lab Communications Specialist Richard Sima. Richard received his Ph.D. in neuroscience from Johns Hopkins and is a science writer living in Baltimore, Maryland. For more articles like this, go to www.artsandmindlab.org

In the middle of lockdown, I was on an island fishing with my girlfriend. After selling our catch at the local store, we took an impromptu date to the museum and aquarium, admiring their collections. And, seeing as we were the only ones there (save for one sleepy museum attendant), we snapped an endless stream of photos to commemorate our pandemic date night experience.

I should note that throughout our adventures, we were still maintaining social distance. We hadn't even left our home, hunkered down on our living room couch, while our virtual avatars ran about freely in the game *Animal Crossing: New Horizons*.

ENJOYING THE VIRTUAL MUSEUM ON OUR PANDEMIC DATE

Given the physical distancing requirements posed during quarantine, it comes as no surprise that games like *Animal Crossing* have exploded in popularity. Even before the pandemic, video games were a staple of entertainment for many households; more than 214 million Americans say they play for one hour or more each week and 75% of households have at least one person who plays. The stereotype that gaming is the sole purview of adolescent boys no longer holds: the average age of gamers is actually 35 – 44 and 41% of gamers are women.

Video games are a unique art form that allows for a whole new level of immersion and interaction in storytelling. The design of a game – including its graphics, animation, character development, soundscape – incorporates many of the creative elements of other art forms. And like other arts, video games can open up another outlet for human expression and escape.

As surging COVID-19 cases limit holiday travel and winter in the northern hemisphere forces people indoors, video games offer a safe way to explore different worlds and meet up with friends – while providing many social, emotional, cognitive, and physical benefits to boot.

PLAYING VIDEO GAMES CAN PROVIDE REAL-LIFE POWER-UPS

Each weekend, my friends and I get together to outwit each other aboard a spaceship in the game *Among Us*, which has also caught on like wildfire during the pandemic. (It has become so popular that Congresswoman Alexandria Ocasio-Cortez recently streamed herself playing *Among Us* to get out the vote for the 2020 election.)

Among Us is a game of social deduction, like *Mafia* or *Secret Hitler*, where innocent crew members need to identify imposters while completing tasks to maintain the ship. The game also provides a chance to catch up with one another and meet friends of friends. In lieu of face-to-face outings, *Among Us* is probably where I get most of my social interaction each week.

Games that include these social components have been found to have positive benefits on psychological wellbeing by providing a virtual space to “hang out” with real-life friends or make online ones, leading to greater closeness and intimacy. These social games may also foster more prosocial behavior. Research has found that cooperative games, like *Overcooked* or *Portal 2*, could promote more empathy and cooperative behavior outside the game for both children and adults.

Video games can also promote emotional regulation, which is handy during These Unprecedented Times. One study found that regular gamers better managed their emotions and were less emotionally reactive than irregular gamers. Another study found that frequent gaming was positively associated with relaxation and coping. This may be because people tend to use video games to recover from stressful situations and negative emotions: simply put, games are fun and contribute to positive emotions and emotional stability. But in addition, games can teach adaptive strategies through storytelling or problem-solving that the player can apply to the real world. And, more directly to our pandemic predicament, a recent pre-print study that has not yet undergone peer review from Oxford reported that playing more video games is, on average, improved mental wellbeing.

Gaming has cognitive benefits as well. Video games are engaging and interactive by design, often incentivizing players to work towards meaningful goals, learn from failure, and accomplish challenging tasks. Numerous studies have found that “action” video games (like *Halo* or *Call of Duty*) may enhance the ability to learn new skills by improving focus and task prioritization. These games are also linked to lasting improvements in spatial skills, even after only a relatively short amount of playtime. Gaming, in general, also improves mental processing speed, reaction times, and memory, suggesting that gameplay changes the brain. One study found that playing the classic game, *Super Mario*, a mere 30 minutes a day was correlated to increased grey matter in brain areas crucial for spatial navigation, strategy planning, working memory, and movement.

Finally, games help us get moving. Video games that incorporate movement (active games or “exergames”) like *Wii Fit* or *Just Dance* can help keep us physically fit in the safety of our own homes. One meta-analysis of 100 studies found that active video games improved physical activity; playing these games regularly can significantly improve physical health outcomes like balance, flexibility, muscle strength, and heart rate. In addition, compared with traditional exercise, exergames are significantly more enjoyable which may help people stick with it over the long-run. And because physical health is interrelated to mental health, exergames can alleviate psychological conditions, such as depression.

As with other activities, moderation is key. If played obsessively, games tend to have a detrimental effect. Indeed, “moderate gamers” have better mental health and psychosocial functioning compared to non-gamers or those who game in excess to the detriment of other areas in one's life, such as relationships, school, work, and sleep. Video games are obviously not the end-all solution to getting through the challenges of the pandemic. But, along with other creative activities (like dancing, baking and gardening), a bit of gaming can provide you the 1-Up you need.

HOW TO GET YOUR GAME ON

The variety and number of games on the market today can be overwhelming, but the good news is that there is something out there for everyone. Here are some games that can help you get started:

CREATIVITY GAMES:

- *Animal Crossing: New Horizons* lets you make a digital island your own and visit those of your friends'.
- *Minecraft* is a genre-defining game that allows you to survive and build your world, one block at a time.
- *The Sims 4* is a life simulator and home builder that allows you to live your best (or worst) life – without the real-world consequences.

DRAWING GAMES:

- *Jackbox Games* offer a fun-pack of competitive and cooperative party games with friends for even the casual gamer. Play *Drawful* to draw ridiculous prompts, trivia games, or *Pictionary* all from your smartphone or tablet.
- Other *Pictionary*-like games are free and easy to join online like *Drawize* and *Skribbl*.

MUSIC GAMES:

- *Audiosurf* lets you race to your own music while *Beat Saber* has you slice through blocks to the beat of the song.

WRITING GAMES:

- *Kind Words* allows you to write (and receive) letters of encouragement and kindness to people around the world (and provides a relaxing soundtrack to listen to while you do so).

SOCIAL DEDUCTION GAMES:

- *Among Us* offers a multiplayer game for hours of teamwork, betrayal, and fun. Available for free on your smartphone or for \$4.99 on your laptop.
- *Codenames Online* allows you and your friends a virtual version of the board game classic. Strategize how to best communicate your secret words to your teammates while keeping your opponents in the dark.

EXERCISE AND MOVEMENT GAMES:

- *Just Dance*, *Wii Fit*, or *Ring Fit* combine interactive elements like music, virtual coaches, and high scores to make working out more fun.
- Games like *Pokémon Go* or *Zombies, Run* add an augmented reality gaming component to encourage physical activity in the outside world while catching critters or escaping from zombies, respectively.

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