Winter 2017, Vol. 35

Bridges

Connecting Cancer Survivors

More Than My Cancer

By Abena-Star Antwine

One question that I hear too often is "What's your story?" To someone else this might sound like a simple question, but for me it's more complicated. Cancer is not my whole story, just a small part of it, because I am so much more than my cancer.

I am a 26-year-old mother of two; I had my first child when I was 16. Without a father in my life, I was raised by my grandmother, because my biological mother struggled with addiction. In 2012, I got my degree in education and had another child. I started my first teaching job three weeks after having my daughter and worked for three years at a local charter school. At the same time, I decided to go back to school and get a master's degree in mathematics. Life was great! I had the perfect man, two amazing children, and I was teaching at a good school. It was a Cinderella happy ending. Unfortunately, not quite.

A week before Christmas in 2014, I woke up with a small, painful lump in my jaw. After many ups and downs, I was diagnosed with Ewing sarcoma the following April. The hospital that diagnosed me was about to operate to remove the mass, which was now inside my jaw, when a scan showed that there was also cancer in my lungs. That's when I was referred to MSK. By this point the lump was huge; I couldn't eat, was only able to drink liquids, and it hurt to talk.

At MSK, the surgeon decided not to operate immediately but to use other options to reduce the mass. So in June 2015, I started treatment.

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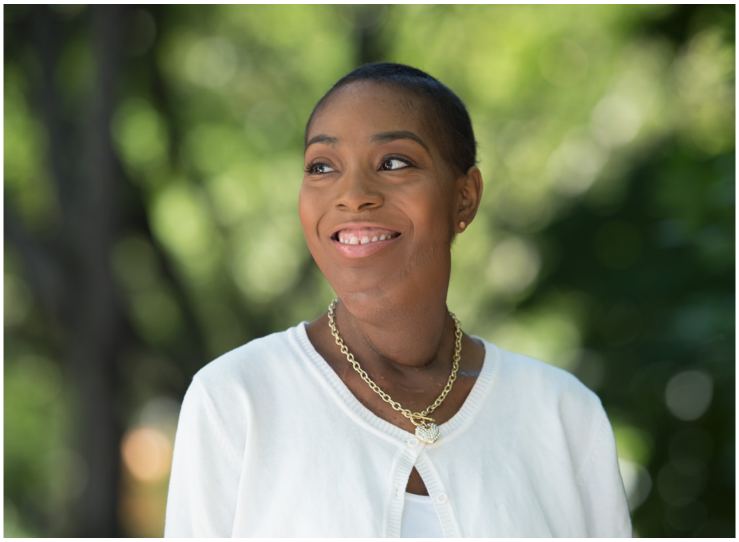
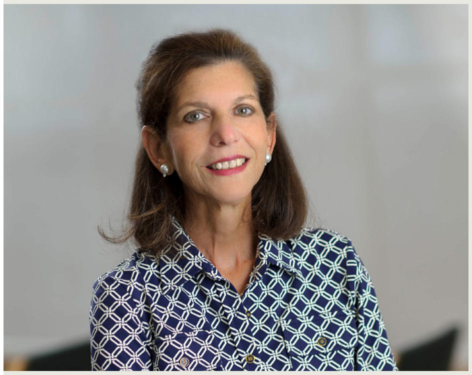


Abena-Star Antwine is a survivor of Ewing sarcoma, a teacher, the mother of two wonderful children, and a newly married wife. In her spare time, she enjoys spending quality time with her children and traveling.

In This Issue

Memorial Sloan Kettering
Cancer Center

Interested in sharing your story?
Please visit **www.mskcc.org/bridges**



Editorial

By Eileen F. Gould

Resilience is the ability to quickly recover from difficulties and challenges; I often read about it in the World of Cancer and Survivorship. Many cancer survivors are able to spring back into shape and are remarkable in their ability to pick up exactly where they left off prior to diagnosis. However, not everyone has that same experience. Some people are left with permanent scars — both physical and emotional.

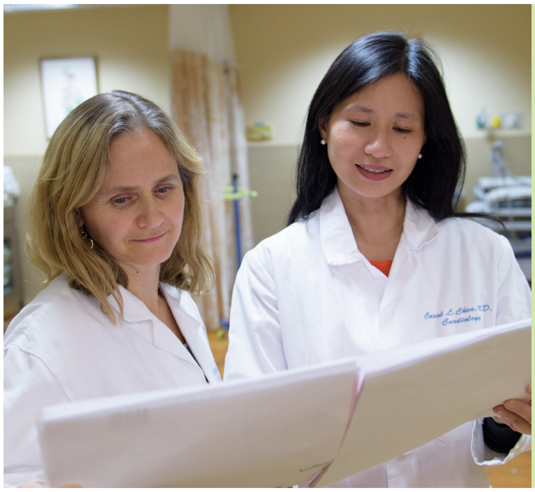
Some cancer survivors may want to have a "second act" after surviving their illness. Perhaps they gain an inner strength and want a chance to transform their life and do something completely different in their job or with their free time. Some survivors start running marathons as a way to show their resilience; others learn new skills or volunteer.

But for some people, merely restarting life with the basics of everyday living, like returning to work, taking care of family, or something as simple as taking a walk, is a major accomplishment. Resilience means different things to different people. Survivorship is a very personal experience. We are all on a path — whether straight or curved — from our illnesses and treatments. We hope that the stories in *Bridges* open a window into the shared experience of survivorship.

Where Are They Now?

Beth Schiff

We all have various titles and ways in which we describe ourselves to those we meet. I surprised myself recently by proudly proclaiming that I am a "nearly 40-year cancer survivor" and was struck by how odd that must sound to most people. Diagnosed in my late teens with Hodgkin's lymphoma and 30 years later with breast cancer, I will mark an important milestone in 2017 — 40 years as a Hodgkin's survivor and ten years as a breast cancer survivor. After many years of unexplained health issues, culminating in my breast cancer diagnosis in 2007, I embraced survivorship and determined that I would try to help other survivors, both current and future, obtain the knowledge and medical attention that had been missing in so many of their lives. I currently chair the University of Cincinnati Cancer Institute Survivorship Program Community Advisory Board as well as the Board of Trustees of my three sons' independent school, the Seven Hills School, also in Cincinnati.



ASK THE PROFESSIONAL

Survivors and Cardiac Late Effects

Carol Chen and Wendy Schaffer are cardiologists who specialize in cardio-oncology at Memorial Sloan Kettering. They take care of cancer survivors as well as current patients. In their spare time, both are active fundraisers for MSK through Cycle for Survival and Fred's Team.

Which cancer survivors are most at risk for heart-related issues that appear long after treatments are over?

People who are most at risk include those who have had radiation that included the heart in the radiation field and those who have received chemotherapy that may affect the heart. Lymphoma survivors have sometimes received radiation near the heart, as well as breast cancer survivors (though usually in lower doses). Survivors of lymphomas, sarcomas, and breast cancer, as well as some other cancers, have often received chemotherapy that can cause long-term cardiac effects.

Survivors who have other heart conditions or risk factors for heart disease may also be at increased risk for late cardiac effects. These include survivors with diabetes, elevated cholesterol, or who smoked cigarettes or are overweight or sedentary. Elevated blood pressure significantly increases the risk of late cardiac effects from cancer treatment. These risks for heart disease become more common as survivors age, as does the risk caused by some cancer treatments. Exposure to some cancer treatments as a child, when the body is still growing, also increases the risk of late cardiac effects. The risk is especially high when treatments that can affect the heart are combined — such as radiation close to the heart and chemotherapy that can affect the heart — or when survivors already have problems with their heart or many risks for heart disease.

What cardiac tests are used for screening?

Cardiac testing helps fill in the picture of each survivor's heart health. The choice of cardiac testing for an individual cancer survivor depends on the prior cancer treatment and the specific risks. An electrocardiogram (EKG or ECG) provides information about the heart's electrical system, which can be diseased in patients who had radiation close to the heart. An echocardiogram provides ultrasound images of the heart's pumping function and valves. This is a useful test for survivors who received cancer treatments such as anthracyclines or trastuzumab, which can weaken the pumping function in a small number of survivors. Survivors who received high levels of radiation close to the heart may be at risk for future heart attacks. A calcium score or a CT scan of the tiny arteries that supply blood to the heart muscle helps identify survivors who may be at risk for a future heart attack. Cardiac stress testing, performed by walking on a treadmill or with medications, can also be used to identify survivors who are at risk for future heart attacks so that this risk can be reduced.

How soon after treatment should a cancer survivor be evaluated for risks and what can they do to lower their risk?

Survivors should ask their doctors about the long-term cardiac effects of their individual cancer treatment and whether regular monitoring of their heart is recommended. Survivors should also tell their doctors if they have any concerning cardiac symptoms, such as shortness of breath or chest pain or pressure, that might be related to their cancer treatment. To reduce the risk of late cardiac effects from cancer treatment, it is very important to protect the heart by exercising, maintaining normal cholesterol and a healthy weight through a heart-healthy diet, avoiding smoking, and keeping blood pressure and blood sugar levels in a normal range. Survivors can ask their primary care doctors, their cancer doctors, and, if available, a cancer survivorship team to assist them in their efforts to maintain their heart health after cancer treatment.

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I missed so much time with my kids because I was frequently sick or in the hospital. And then, in October, my boyfriend proposed. It was the best moment of the year for me and it gave me so much strength. Although I missed birthdays, celebrations, and family time, I was blessed to be able to come home two days before Thanksgiving for a beautiful meal prepared by my fiancé. I stayed out of the hospital and was home for Christmas and the New Year.

After radiation, I continued chemotherapy. The good news was that the cancer in my lungs was almost gone and I wasn't in the hospital as much; 2016 was going to be my year. I was going to get rid of cancer and get married, both in one year.

February flew by. My lungs continued to look better, but not the cancer in my jaw. By April, the cancer in my lungs was completely gone, but the tumor on my face was worse. It looked like a fungus and carried a repugnant smell. I had a breakdown at the thought of having to go through life like this. But God heard my prayers. One week later, the surgeon decided to operate.

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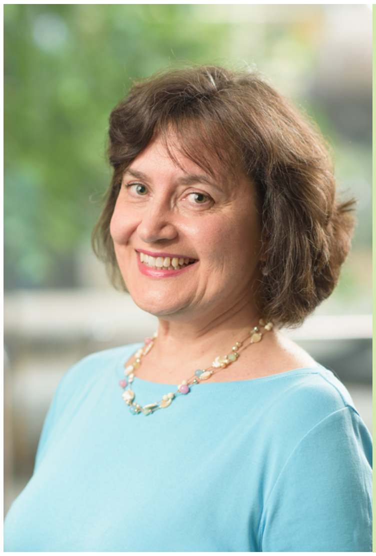
Rising Voices is a fun and lively singing group just for patients and survivors. Open to all MSK patients, Rising Voices is a free, supportive activity sponsored by the Integrative Medicine Service.

To join, please contact
Brigid Judge at
brigidcj@gmail.com or
call 646-888-0800.



The Kindness of Strangers

By Lucille M. Kennedy

Retired editor Lucille M. Kennedy and her husband, Bob, now split their time between Westchester and San Francisco Bay. An avid reader, Lucille also enjoys travel, family research, hiking, bridge, and the culinary arts.

For as long as I can remember, books have given me insight, pleasure, and comfort. Wherever I am — on a business flight to Tokyo or lounging by the Montauk shore — chances are I'll be reading a good book. How fortunate I've been to have had a long career in book and magazine publishing, immersed in the printed word.

Two years ago, I was facing combined pancreas and kidney surgery at MSK for a rare cancer syndrome. A comment in the novel I was reading at the time resonated with me: "You can't help things you feel, only things you do." Wow, that was true. I couldn't help feeling overwhelmed, scared, a bit angry, sad. Especially, worried — I am a big worrier: How can I tell my dad in Florida and my son and daughter out in San Francisco that I have cancer? Will I be brave enough to get through the surgery? And the biggest worry of all: Will I ever be ME again?

To counter the negative feelings, I focused on things I could do to prepare for my surgery. I surrounded myself with positive, caring friends and family members, and I let my husband and twin sister be partners in the process. I prepared and froze some favorite recipes for my recovery. I started a knitting project, signed up for online bridge, downloaded music, and set aside a stack of must-read books.

Recovering on M16 post-surgery, however, I soon realized that there wasn't much I could actually do. I wasn't up to reading; even knitting a few rows wiped me out. But still I needed a plan. In the middle of my career, I was a Reader's Digest features editor. I once ran this J.M. Barrie quote in my "Quotable Quotes" column: "Always try to be a little kinder than necessary." That was it; I was going to focus on the kindness of strangers. It became a game of sorts for me, noting who would make My List: medical student Rory, who cheerfully walked me to the OR. Margaret, my first night nurse, whose skill and compassion got me through the tough hours. PCN Terry, who gently gave me my first post-op shower. They and many other caring professionals made My List. Somehow, I promised myself, I would find a way to thank them.

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RESOURCE REVIEW

Resources for Life After Cancer

By Barbara Golby, LCSW-R

“Congratulations, you’re done with treatment!” These are words that many people undergoing treatment for cancer can’t wait to hear. The shock of diagnosis, rigors of treatment, and overall upheaval that cancer causes can leave you yearning to feel like yourself again. Patients are often eager to get back, first and foremost, to feeling healthy. But there are many other important aspects of life that may have been put on hold such as work, family, friends, hobbies, and vacation that need to resume when treatment is over.

Many people are surprised to find that getting back into life after treatment is not as easy as they thought it would be. At a time when patients look forward to feeling grateful and relieved to be finished, they may also feel sad, angry, anxious, guilty, and very alone. Although it might seem strange that these feelings would emerge once treatment is over, it is actually quite normal. So how does one begin to move forward?

Resources for Life after Cancer (RLAC) is a Memorial Sloan Kettering program that provides support to patients after they have finished treatment. The program was started in 1990, under the name Post-Treatment Resource Program, to address the unique emotional and practical concerns that arise during the period following the completion of active treatment. RLAC’s services include individual and family counseling, support groups, educational seminars and workshops, and community referrals. Services are provided by clinical social workers with special training and expertise in the area of cancer survivorship.

The support groups bring together patients who are at similar life stages or have similar diagnoses. Through the sharing of experiences, these forums provide an opportunity to better understand one’s reactions and feel less alone, receive validation, and learn new strategies for managing post-treatment concerns. Short-term counseling is available to those who seek individualized support that integrates their cancer experience.

Workshops and individual consultation are also provided in specific areas such as employment, insurance, and dating after cancer. Educational seminars are designed to empower patients and family members with information to better understand and manage the long- and short-term side effects of treatment. Clinicians from throughout the MSK community are invited to present on topics ranging from managing fatigue to speaking with your healthcare team about your post-treatment concerns.

Individual support is available in person or over the phone. Most support groups and educational seminars are conducted in person. However, many are offered online in conjunction with MSK’s Virtual Programs. Patients can find out more about RLAC by emailing RLAC@mskcc.org or calling 646-888-8106.

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Back home, I gradually increased the things I could do. Eating and digesting food can be challenging after pancreas resection. Again, worries crept in: Will I ever get my appetite back? Will food taste good again? On a bright July day, I walked out onto my deck and picked the first tiny tomato of summer. I slowly ate that minuscule sun-kissed tomato, seasoned only with my salty tears. Nothing could be more delicious.

And true to my word, I typed up a long letter, thanking all the people on My List, and mailed it to MSK’s Patient Representatives department. To my delight, I received a letter back, informing me that everyone I had mentioned, plus his or her supervisor, got a copy of my letter. A little kindness, it seems, goes a long way.

Visible Ink™

A One-on-One Writing Program
for MSK patients

Interested patients will work individually with the guidance, encouragement, and support of a professional writer on a topic and project of their choice. This program is FREE. All levels and writing interests welcome.

For more information or to arrange a writing session, please contact Judith Kelman at 212-535-3985 or kelmanj@mskcc.org.

ASK THE SURVIVOR

Survivors and Cardiac Late Effects

By Danny Tavarez

Danny was born in the Dominican Republic on Valentine's Day in 1977; he and his younger siblings were raised in New York City by their wonderful mother. He currently calls Washingtonville, NY home with his lovely wife and his three children. He's a survivor, a proud husband and father, and the heart and soul of his family.

What kind of cancer did you have and what treatments did you receive?

When I was just nine years old, in 1986, I was diagnosed with Hodgkin's lymphoma. Before I had even reached puberty, my life had changed dramatically. At the time I was too young to understand the full impact my cancer and its treatment could potentially have on my life, but I knew that I wouldn't have a typical childhood or future. The December after my diagnosis I started radiation and chemotherapy treatments; I was prescribed six cycles of procarbazine along with doxorubicin, cyclophosphamide, and vincristine. After just a month of treatment, I was so sick and fragile.

Because of the cancer treatments that I received, my parents were informed that there could be some potential long-term effects. One of those effects was cardiovascular problems.

How soon after your treatment did you learn of your cardiac late effects? Are your cardiac issues a result of your cancer treatment?

As part of my survivorship plan, I have attended routine follow-up visits annually since I completed my cancer treatments back in 1989. I never experienced any noticeable cardiac symptoms. But at my annual appointment in February 2014, my physician saw that the results of my electrocardiogram (EKG) and stress test were not consistent with my previous tests. Based on this, she sent me to have a cardiac catheterization, which is used to diagnose some cardiovascular conditions. That's when we learned that my artery was blocked. Because of the radiation and chemotherapy that I had undergone as treatment for my cancer, my heart had taken a lot of stress, and it resulted in me needing to have a bypass procedure.

I had grown used to the madness of all the annual testing. It made me become desensitized. When I learned about my heart problems, I felt scared for the first time in my life. It was the first time as an adult that I understood I was very fortunate to be alive. I felt very blessed by all the things I was able to do and accomplish given my prognosis.

What kind of treatments or surgeries did you have for your cardiac post-treatment effects? And what kind of ongoing monitoring do you have to maintain your cardiac health?

Soon after my cardiac catheterization, I went in to have my heart bypass surgery to restore the blocked coronary artery. The first two months after my bypass surgery were pretty rough; it was hard for me to walk and even sleep, my appetite wasn't the same, and I constantly felt cold. I started attending rehabilitation and began to feel better. I did rehab three times a week, which included exercise using a treadmill, bike, and stair machine along with relaxed walking and some light weightlifting.

After the surgery I continued to attend annual physical exams that included stress tests, EKGs, and pulmonary function testing to ensure all remains well.

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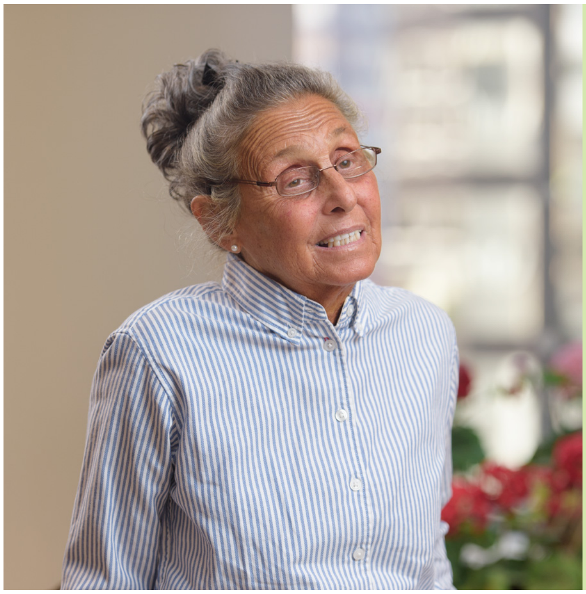

Just One of the Crowd

By Diane McNiff

Diane McNiff is a retired insurance administrator and pre-K teacher. She is the proud mother of two and the grandmother of one. Her interests include reading, writing, painting, and living in the moment with family and friends. She recently celebrated her 70th birthday and always tells people she is very proud of every gray hair and wrinkle that she has.

Early on in my venture with immunotherapy, I was often told how remarkable my response was, and this made me feel unique. Now that I am in survivorship, I'm pleased to say I feel like I am one of a growing number of people who had a positive response to immunotherapy treatment. I'm no longer unique, just one of the crowd — and that's a powerful testament to how far we are progressing.

My story begins in December 2012, when I began experiencing pain in my side. I went to my primary care physician to have it checked out. When he called me back to his office, it was to tell me that I had cancer. He suggested that I get my affairs in order and told me it was OK to be angry or cry. But I thought, What good would that do? My job was to put one foot in front of the other, share this news with my family, and get moving. I have a small family: my daughter, son-in-law, and granddaughter; my son; and my brother. Their response was totally supportive. Someone was always with me for my appointments.

My doctor sent me to Memorial Sloan Kettering, where I was diagnosed with stage IV metastatic lung cancer that had spread to my bones, pancreas, and parotid gland. The prognosis was grim, but we began chemotherapy. Six months, three different cycles — none of which worked. I lost my hair, my weight dropped to 80 pounds, and the only time I left my house was to go to my medical appointments.

As a last resort, in June 2013, I was offered a clinical trial in immunotherapy. At first we weren't sure if I was strong enough to participate, but it began to work, and with each passing scan my tumors shrank, my hair grew back, I gained weight, and my energy returned.

The treatment continued for 22 months. During that time I was able to do things I thought I would never do again. But in May 2015, the tumors in my lungs began to grow. We were devastated. I was taken off the clinical trial and, at the suggestion of my oncologist, underwent lung surgery to have two lobes removed. Recovery went well but was not without its challenges. I was put back on immunotherapy again, and right now, things seem to be looking good. I'm having some issues with joint and muscle pain that we are trying to control with medication, but surely this is manageable.

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Do you exercise regularly and/or follow a special diet?

Being a cancer survivor in general forces certain lifestyle changes and routines, but those were the very things that helped everyone involved with my care find a way to help me live the most normal life possible. I struggled during adolescence with depression and feeling as if I would never be able to have a family of my own. But I met my wonderful wife and we have since adopted our wonderful children. My mother helped set the blueprint with my diet and exercise routines and then taught my wife how to care for me as well. This has been an ongoing struggle, but we work well as a team. The goal is to live a long and healthy life.

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When my cancer journey began, it was questionable if I would make it to the next holiday. But since then I have seen my daughter marry and my son graduate college and watched my beautiful granddaughter grow. My family, friends, and in particular my two best friends from college have been there every step of the way. I am so blessed in that respect. Being treated at MSK has also been a blessing. My wonderful oncologist — who practically bounces into the room when my scan results are good — and the nurses who care for me are truly remarkable.

As foolish as it may sound, I often think about how grateful I am to be on this journey. Cancer gives you such a profound appreciation for life and all the beauty and goodness in this world. Again, I find it surprising that many others who travel this road experience similar feelings; I'm not unique, just one of a crowd.

I just celebrated my 70th birthday with my family and a few friends at a small restaurant that I am fond of. At some points I didn't think that would ever happen. Call it outstanding medical care or call it a miracle — whatever you call it, I'm still here!

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June 6 was my scheduled operation day, two days before my son graduated as valedictorian of his elementary school. Although I wasn't able to attend graduation, the surgeon was able to remove the multiple tumors he found, leaving the jaw intact.

The 80 pounds I lost, the flaccid skin and muscle, and the stitches all over are testimony to this portion of my story. But I am alive and well and cancer free. It has been a long, emotional journey, and I made it. The cancer is gone, but the road ahead is still long and challenging.

As I write this, I have a month and a week to get ready for my wedding. I'm looking forward to returning to school and teaching, and many, many years of joy with my family. See, my story still continues — even beyond cancer.

Memorial Sloan Kettering
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Patient and Caregiver Volunteer Program

The Patient and Caregiver Volunteer Program connects current patients and caregivers to volunteers who have experienced a similar diagnosis or circumstance related to cancer. If you are a former patient or caregiver of someone who has completed treatment, please consider becoming a Patient or Caregiver Volunteer.

For more information, contact Wendy Bonilla at 212-639-5007 or patient2patient@mskcc.org.

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