

Learn about
the latest
treatment
options

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Get the
emotional
support
you need

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“I want to
change
the face
of MS!”

Multiple Sclerosis

Victoria Reese has a mission: to help other people of color and millennials diagnosed with MS feel represented and understood—and get properly treated



“My MS treatment allows me to focus on what’s important—like being a great mom to Harper,” says Victoria.

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“I want to change the face of MS!”

Victoria Reese has a mission: to help other people of color and millennials diagnosed with MS feel represented and understood—and get properly treated

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LUJ23

Cover photo by ChuckMarcus Photography

Life can be all you dreamed—even if you have MS

Despite its reputation as a “White person’s disease,” Black people do, in fact, get multiple sclerosis (MS)—and their numbers are on the rise. Luckily, staying attuned to the signs, getting a timely diagnosis and partnering with your healthcare team can lead to effective treatment—and make all the difference in the world. —BY TONYA RUSSELL

To hear her tell it, **Victoria Reese** is “living a dream realized.” After all, she’s in the middle of spiffing up the house she just bought, is excited about being newly engaged, is raising three-year-old daughter Harper and is running Victor Group Creative, her own brand strategy and consulting group. (See p. 8)

Meanwhile, **Dawnia Baynes** is busy exercising, going to her beloved Dodgers games and attending live concerts—that’s in addition to leading her own nonprofit, called Brightside 365. (See p. 16)

As for **Harvella Printup**, the full-time legal assistant manages to squeeze in travel, make time for meditation and other forms of self-care and inspire others through support groups she facilitates. (See p. 18)

What these vibrant Black women all have in common? They’re living with multiple sclerosis (MS)—and not letting the disease, which affects the central nervous system, get the best of them. In fact, they’re proof that advocating for yourself, being an active participant in your healthcare, following your treatment plan and staying engaged with others can help you thrive.

Continued on next page ▶



If you are a Black person with MS, know that like Victoria, Dawnia and Harvella, you, too, can do the things you love and be optimistic about the future. Start by reading this guide to learn more about the disease, how it affects Black people in particular, the treatment options available to you and the strategies that can help you make the most of every day!

Understanding the basics

MS is a chronic autoimmune condition that causes your body to attack myelin, the protective sheath that surrounds the brain's nerve cells, as well as the nerve itself. When myelin breaks down, messages between the brain, spinal cord and other parts of the body get delayed. That slowed communication leads to a range of complications that can affect the way you think (trouble remembering information, for example) and the way you move and feel (e.g., you may lose your balance or experience numbness).

How does MS manifest in Black patients?

Until recently, doctors thought MS was a White person's disease, with most cases tied to European ancestry. But current statistics tell another story: Not only are diagnoses on the rise among the Black community, but rates of the disease among Black women don't lag far behind those of White women. Three in 1,000 Black people are diagnosed with MS compared with 3.75 in 1,000 White people. Unfortunately, the misconception can still cause the disease to be missed in Black people.

In truth, despite the fact that MS symptoms among White and Black people are essentially the same, they often are not detected in Black people until they are more pronounced or chronic—and the disease more advanced. That's why it's important to alert your doctor immediately if you notice any of the following. The sooner you get help, the lower your chances of MS causing you to become disabled:

- Sudden, painful vision loss or color changes, often in one eye
- Problems with balance, walking, and coordination



- Trouble with memory, attention and understanding information
- Extreme fatigue
- Muscle stiffness
- Numbness, tingling or pain
- Slurred speech
- Bladder and bowel problems

How is it diagnosed?

MS is usually diagnosed by first ruling out conditions with similar symptoms, such as fibromyalgia and Lyme disease. Blood tests and spinal taps can check for antibodies related to myelin

damage. And an MRI to look for lesions—i.e., myelin damage on the brain and spine—is crucial to diagnosis. Although most people are diagnosed between the ages of 20 and 40, Black patients are often diagnosed at later ages.

For one, false beliefs about MS being a “White person's disease” can stand in the way of a timely diagnosis. For another, some Black people may not have easy access to a neurologist who can run tests. Consider that in 2021, 12.7% of Black workers were uninsured compared to 7.5% of White workers, according to CDC reports. Black adults are also less likely to have paid time off

(PTO) or paid sick leave, so it's hard for them to even get to a doctor.

And while MS appears to be more prevalent in the Northeast and Midwest than in the South or West, those numbers may actually be a reflection of people living in “care deserts”—places with fewer options for proper diagnostics and treatment.

Who gets it?

An estimated 947,000 Americans have MS. Race is often missing from patient data, but it is estimated that 3 out of every 1,000 Black people

MS AT A GLANCE

THREE
out of
1,000

THE NUMBER OF BLACK AMERICANS DIAGNOSED WITH MS.

20-40
THE TYPICAL AGE RANGE FOR DIAGNOSIS.

3X
HOW MUCH MORE LIKELY WOMEN ARE TO DEVELOP MS THAN MEN.

develop MS. While the disease affects people of all ages, most are diagnosed between ages 20 and 40, with women about three times more likely than men to develop the condition.

What are the types?

About 85% of those diagnosed have relapsing remitting multiple sclerosis (RRMS)—that’s when periods of no disease activity (remission) alternate with flare-ups (i.e., a relapse or exacerbation). Two other common forms of MS are primary-progressive MS (PPMS), which is marked by a steady worsening of symptoms without any relapses, and secondary-progressive MS (SPMS), where symptoms gradually worsen, and relapses may or may not occur.

How is it treated?

Taken regularly, disease modifying therapies (DMTs) help reduce MS relapses and thus potentially help to slow progression of the disease. Nearly 20 different DMTs are FDA-approved for

the long-term treatment of MS. They are available in pill form and by injection and infusion; the majority of them work by modifying the immune system to prevent it from attacking myelin, the protective coating around nerves.

The American Academy of Neurology issued guidelines recommending that for most people, it can be better to start treatment with a DMT as soon as possible—even if symptoms are mild—because early treatment can help slow the disease process and may help keep your condition stable. There are also treatments available to help speed recovery if your MS relapses.

Lifestyle strategies

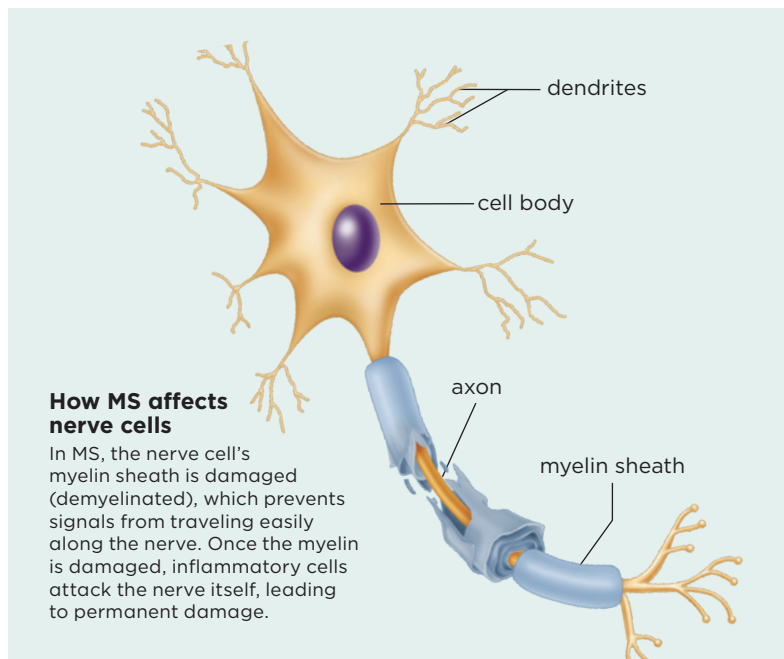
Adopting healthy behaviors not only boosts your overall health, it may also slow the progression of your MS. If you need help making changes in your life, reach out to your family and friends for support.

• **Eat nutritious meals.** There’s no “MS diet,” but research suggests a

diet low in saturated fat and supplemented with omega-3 fats (such as from fatty fish like salmon) and omega-6 fats (from sunflower or safflower oil) may have benefits for people with MS.

- **Exercise.** Activity that suits your capabilities can boost your mood, strength, cardiovascular fitness and even bladder and bowel function.
- **Manage your stress.** Your MS symptoms may worsen during times of stress. Eliminating or minimizing your stressors and reaching out to family and friends for support can lift your spirits and make your days more pleasant.
- **Stay cool.** Getting overheated—whether from exercising, hot outdoor temperatures or taking a steamy bath—makes it harder for damaged nerves to transmit electrical impulses, leading to temporary worsening of MS symptoms, aka “pseudorelapses.”
- **Get enough rest.** Adequate quality sleep can help safeguard your mood, cognitive abilities and physical well-being, helping you to avoid spasticity, pain and balance problems.

Here’s the good news: The more motivated you are to work with your healthcare team and try the lifestyle strategies and other treatments as prescribed, the better your odds of living your best life with MS. The critical piece? Opening up about your symptoms. With so many treatment options available—from disease modifying therapies (DMTs) to treatments for relapses and therapies for symptom relief—finding what works for you is a matter of trial and error. Let your care team know what you’re coping with, so they can help you find relief or adjust your treatment as needed. ●



Who’s on your healthcare team?

These are the healthcare professionals who will support you through your MS journey.

Primary care provider (PCP): an internist or family physician who manages and coordinates your overall care. Your PCP may have referred you to a neurologist for your MS care.

Neurologist: a doctor who specializes in diseases involving the nervous system and who will create a treatment plan for you.

Nurse: a medical professional who can answer questions, provide guidance and help you follow through with your treatment and self-care. Some nurses are MS-certified and have received advanced training in MS care.

Neuropsychologist: a doctor who will develop a care plan to address the cognitive effects of MS and boost your mental functioning.

Physiatrist: a doctor who will develop a care plan to address the physical effects of MS and boost your physical functional abilities.

Physical therapist (PT): a licensed healthcare professional who can help you manage your MS symptoms through movement and exercise.

Occupational therapist (OT): a licensed healthcare professional who can make recommendations to help you function your best while at home, work or out-and-about.

Speech-language pathologist (SLP): a licensed healthcare professional who can assess, diagnose and treat many types of communication and swallowing problems.

Dietitian: a licensed nutrition professional who can help you eat well to feel your best.



COVER STORY

“I want to change the face of MS!”

Back in 2012 when Victoria Reese was diagnosed with relapsing remitting multiple sclerosis, she looked around at the resources out there for MS patients and noticed a problem: “I thought, ‘Where are the Black people? Where are the millennials? Where are the people that are like me?’ ” So she decided to do something about it. Today, she works every day to help change that as the founder of the nonprofit patient advocacy organization We Are ILL—all while managing her own care. —BY BETH SHAPOURI



Victoria Reese's journey with relapsing remitting multiple sclerosis started, as it does for many with the condition, with some tingling in her legs. After an initial misdiagnosis of stress and depression, she eventually was sent for a brain scan that showed telltale MS lesions. Despite her symptoms, she was

surprised to hear she had MS—the only people she could think of who had the condition were a friend's wheelchair-bound mom, Richard Pryor, and TV host Montel Williams. There was no one in her immediate circle she could turn to for understanding or advice.

Victoria was immediately started on a disease-modifying therapy medication—a monthly injection that inhibits her immune system from attacking the myelin on her nervous system cells. While it helped to “dim down” her relapsing symptoms, she still wanted to dig more deeply into her situation and options.

Continued on next page ►

“Like any millennial, I took to the internet to figure out my new normal,” she says. She learned more about the condition, including that the stress of her job at a talent agency was likely worsening her symptoms, leading her to leave her position there.

However, she was frustrated to find that almost all the pictures representing the condition were of older White patients. Of the few she saw who were Black, they were also older. Overall, everything she saw “didn’t really represent me, race-wise, age-wise, or mobility-wise,” she says.

VICTORIA’S TOP TIPS FOR THRIVING, DESPITE MS

Ask your healthcare team if her tips could help you, too.



CONSIDER PSYCHOTHERAPY.

Victoria initially met with a counselor with the intent of learning how to better help other people in her MS support group—but quickly realized the tools the therapist provided were essential for her, as well. “I learned how important my mental health is to the rest of my body, and that has made a huge impact—it’s difficult to get your body feeling well when your mind isn’t there.”

GET SUPPORT.

One of the questions Victoria asks the MS patients who reach out to her: “Who is there to help you out?” Connecting with other patients can be important, as Victoria herself found out. “But it goes even deeper. You need the people in your life to help you navigate this thing, go with you to doctor appointments—things like that. If a partner or family member isn’t available, try connecting with close friends or anyone who can be there for you.”

STAY INFORMED.

Victoria believes in taking charge as a patient and being an active member of your own healthcare team. She suggests other patients get a notebook and write things down when speaking to people from insurance companies, pharmacies and doctors’ offices. As a patient, she says, “You ultimately have to advocate for yourself to navigate through this right.”

“I needed to forge a new path”

If she couldn’t find an existing community, Victoria decided she had to make one. To start, she began posting about her life with MS on Instagram under the handle *@picturethisvic*. “I was using it as my journal, like a digital diary,” she explains.

Over the years she gathered a following and created a network of like-minded Black women with the condition, which emphasized to her the importance of representation and community for those like her.

Then, when scrolling through social media one day, she came upon the Nas album *Illmatic*. “I was like, ‘Wow, I know about this album, but I have never noticed that the word ‘ill’ is in the name.’” Seeing it used in a positive light, she suddenly saw the potential in the word to empower other Black women who have received an MS diagnosis.

“That’s when I created the hashtag, #WeAreILLmatic and I started to create content under it. I did photos and videos to tell my story.” To Victoria’s amazement, Nas reposted her very first video for the campaign to his followers, causing it to go viral.

“Making an impact gives me purpose”

With the success of that campaign, in 2020 Victoria founded We Are ILL, a nonprofit organization focused on promoting health equity and supporting and educating Black women with multiple sclerosis.

“It’s a sad thing to be diagnosed,” she says. “But for me to be able to turn around and help other people, it’s been career highlight for me.”

Today, Victoria’s RRMS is still well-managed thanks to the disease-modifying therapy medication she was started on, and she’s keeping her gaze set on the future, including taking on the role of founder and CEO of the brand strategy and consulting group Victor Group Creative. “Having MS is never easy, but it also hasn’t held me back. I’m a mom—my daughter, Harper, just turned three. I just bought a new house. I just got engaged. I’m living a dream realized!” ●

Photos by ChuckMarcus Photography

YOU & YOUR CARE TEAM

Is it an MS attack?

It’s not always easy to tell when you’re having an MS attack. After all, they can be unpredictable, vary from person to person, and vary from episode to episode. Tracking your symptoms can prompt you to get immediate care, which helps to reduce inflammation, speed recovery from an attack and minimize disability.

Take note of your symptoms

Fill in the worksheet below—but report a suspected MS attack ASAP to your doctor.



Date that your new or worsening symptom(s) began:	How long did the symptom(s) last (e.g., hours, days):	Describe the symptom(s):	Questions/comments for your doctor:
8/15/2023	2 days	Left leg suddenly went numb.	Is this an MS attack? What can I do?

It may be an MS attack if your symptoms...

- are either new or are old MS symptoms that have worsened
- have lasted for at least 24 hours (and often days to weeks)
- are occurring at least 30 days after your last attack
- cannot be explained by anything else (for example, a fever, illness or overexertion)



**MY RELAPSING MS TREATMENT
FITS INTO MY LIFE,
NOT THE OTHER WAY AROUND.**
— WALT D.



- ✓ **Powerful results** for reducing rate of relapses, reducing active lesions, and slowing disability progression*
- ✓ **And proven safety***
- ✓ **Plus, when ready to take, it's less than one minute a month***

Ask your doctor about KESIMPTA today.

MS= multiple sclerosis.
For adults only. Walt D. takes KESIMPTA and has been compensated for his time.
*In 2 studies vs AUBAGIO® (teriflunomide).
*Once monthly after 3 weekly starter doses. Typical injection time; ensure indicator is full and stops moving.

Visit [kesimpta.com](https://www.kesimpta.com) or scan here to see more stories like Walt's.



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Indication

What is KESIMPTA (ofatumumab) injection?

KESIMPTA is a prescription medicine used to treat adults with relapsing forms of multiple sclerosis (MS) including clinically isolated syndrome (CIS), relapsing-remitting disease, and active secondary progressive disease.

It is not known if KESIMPTA is safe or effective in children.

Important Safety Information

Who should not take KESIMPTA?

Do NOT take KESIMPTA if you have active hepatitis B virus (HBV) infection.



Novartis Pharmaceuticals Corporation
East Hanover, New Jersey 07936-1080

Important Safety Information (cont)

What is the most important information I should know about KESIMPTA?

KESIMPTA can cause serious side effects such as:

- **Infections.** Serious infections can happen during treatment with KESIMPTA. If you have an active infection, your healthcare provider (HCP) should delay your treatment with KESIMPTA until your infection is gone. KESIMPTA taken before or after other medicines that weaken the immune system may increase your risk of getting infections. Tell your HCP right away if you have any infections or get any symptoms including painful and frequent urination, nasal congestion, runny nose, sore throat, fever, chills, cough, or body aches.
- **HBV reactivation.** If you have ever had HBV infection, it may become active again during or after treatment with KESIMPTA (reactivation). If this happens, it may cause serious liver problems including liver failure or death. Before starting KESIMPTA, your HCP will do a blood test to check for HBV. They will also continue to monitor you during and after treatment with KESIMPTA for HBV. Tell your HCP right away if you get worsening tiredness or yellowing of your skin or the white part of your eyes.
- **Progressive Multifocal Leukoencephalopathy (PML).** PML may happen with KESIMPTA. PML is a rare, serious brain infection caused by a virus that may get worse over days or weeks. PML can result in death or severe disability. Tell your HCP right away if you have any new or worsening neurologic signs or symptoms. These may include weakness on one side of your body, loss of coordination in arms and legs, vision problems, changes in thinking and memory, which may lead to confusion and personality changes.
- **Weakened immune system.** KESIMPTA taken before or after other medicines that weaken the immune system could increase your risk of getting infections.

Before you take KESIMPTA, tell your HCP about all your medical conditions, including if you:

- Have or think you have an infection including HBV or PML.
- Have ever taken, currently take, or plan to take medicines that affect your immune system. These medicines could increase your risk of getting an infection.
- Have had a recent vaccination or are scheduled to receive any vaccinations.
 - You should receive any required 'live' or 'live-attenuated' vaccines at least 4 weeks before you start treatment with KESIMPTA. You should not receive 'live' or 'live-attenuated' vaccines while you are being treated with KESIMPTA and until your HCP tells you that your immune system is no longer weakened.
 - Whenever possible, you should receive any 'non-live' vaccines at least 2 weeks before you start treatment with KESIMPTA.
 - Talk to your HCP about vaccinations for

your baby if you used KESIMPTA during your pregnancy.

- Are pregnant, think that you might be pregnant, or plan to become pregnant. It is not known if KESIMPTA will harm your unborn baby. Females who can become pregnant should use birth control (contraception) during treatment with KESIMPTA and for 6 months after your last treatment. Talk with your HCP about what birth control method is right for you during this time.
- Are breastfeeding or plan to breastfeed. It is not known if KESIMPTA passes into your breast milk. Talk to your HCP about the best way to feed your baby if you take KESIMPTA.

Tell your HCP about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

How should I use KESIMPTA?

See the detailed Instructions for Use that comes with KESIMPTA for information about how to prepare and inject a dose of KESIMPTA and how to properly throw away (dispose of) used KESIMPTA Sensoready pens or prefilled syringes.

- Use KESIMPTA exactly as your HCP tells you to use it.
- Your HCP will show you how to prepare and inject KESIMPTA the right way before you use it for the first time.
- **Do not** inject into areas where the skin is tender, bruised, red, scaly or hard. Avoid areas with moles, scars, or stretch marks.

KESIMPTA may cause serious side effects including:

- **Injection-related reactions.** Injection-related reactions are a common side effect of KESIMPTA. Injecting KESIMPTA can cause injection-related reactions that can happen within 24 hours (1 day) following the first injections and with later injections. Talk with your HCP if you have any of these signs and symptoms:
 - **at or near the injection site:** redness of the skin, swelling, itching, and pain or
 - **that may happen when certain substances are released in your body:** fever, headache, pain in the muscles, chills, and tiredness.
- **Low immunoglobulins.** KESIMPTA may cause a decrease in some types of antibodies. Your HCP will do blood tests to check your blood immunoglobulin levels.

The most common side effects of KESIMPTA include:

- Upper respiratory tract infection, with symptoms such as sore throat and runny nose, and headache.
- Headache.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see accompanying Consumer Brief Summary on the following page.

The risk information provided here is not comprehensive. This information does not take the place of talking with your doctor about your medical condition or treatment.

To learn more about KESIMPTA (ofatumumab) injections, talk to your doctor or pharmacist. For more information and to obtain the FDA-approved product labeling, call 1-888-669-6682 or visit www.kesimpta.com.

What is the most important information I should know about KESIMPTA?

KESIMPTA can cause serious side effects, including:

Infections. Serious infections can happen during treatment with KESIMPTA. If you have an active infection, your healthcare provider should delay your treatment with KESIMPTA until your infection is gone. KESIMPTA taken before or after other medicines that weaken the immune system may increase your risk of getting infections.

Tell your healthcare provider right away if you have any infections or get any symptoms including painful and frequent urination, nasal congestion, runny nose, sore throat, fever, chills, cough, or body aches.

- **Hepatitis B virus (HBV) reactivation.** Before starting treatment with KESIMPTA, your healthcare provider will do blood tests to check for HBV. If you have ever had HBV infection, the HBV may become active again during or after treatment with KESIMPTA. Hepatitis B virus becoming active again (called reactivation) may cause serious liver problems including liver failure or death. You should not receive KESIMPTA if you have active hepatitis B liver disease. Your healthcare provider will monitor you for HBV infection during and after you stop using KESIMPTA. Tell your healthcare provider right away if you get worsening tiredness or yellowing of your skin or white part of your eyes during treatment with KESIMPTA.

- **Progressive Multifocal Leukoencephalopathy (PML).** PML may happen with KESIMPTA. PML is a rare, serious brain infection caused by a virus that may get worse over days or weeks. PML can result in death or severe disability. Tell your healthcare provider right away if you have any new or worsening neurologic signs or symptoms. These may include weakness on one side of your body, loss of coordination in arms and legs, vision problems, changes in thinking and memory which may lead to confusion and personality changes.

Weakened immune system. KESIMPTA taken before or after other medicines that weaken the immune system could increase your risk of getting infections.

What is KESIMPTA?

KESIMPTA is a prescription medicine used to treat adults with relapsing forms of multiple sclerosis (MS) including:

- clinically isolated syndrome
 - relapsing-remitting disease
 - active secondary progressive disease
- It is not known if KESIMPTA is safe or effective in children.

Do not use KESIMPTA if you:

- have active hepatitis B virus infection.

Before using KESIMPTA, tell your healthcare provider about all of your medical conditions, including if you:

- have or think you have an infection, including HBV or PML. See **"What is the most important information I should know about KESIMPTA?"**
- have ever taken, currently take, or plan to take medicines that affect your immune system. These medicines could increase your risk of getting an infection.
- have had a recent vaccination or are scheduled to receive any vaccinations.
 - **You should receive any required 'live' or 'live-attenuated' vaccines at least 4 weeks before you start treatment with KESIMPTA.** You should not receive 'live' or 'live-attenuated' vaccines while you are being treated with KESIMPTA and until your healthcare provider tells you that your immune system is no longer weakened.
 - **Whenever possible, you should receive any 'non-live' vaccines at least 2 weeks before you start treatment with KESIMPTA.**
 - Talk to your healthcare provider about vaccinations for your baby if you used KESIMPTA during your pregnancy.
- are pregnant, think that you might be pregnant, or plan to become pregnant. It is not known if KESIMPTA will harm your unborn baby. Females who can become pregnant should use birth control (contraception) during treatment with KESIMPTA and for 6 months after your last treatment. Talk with your healthcare provider about what birth control method is right for you during this time.
- are breastfeeding or plan to breastfeed. It is not known if KESIMPTA passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby if you take KESIMPTA.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

Know the medicines you take. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I use KESIMPTA?

See the detailed Instructions for Use that comes with KESIMPTA for information about how to prepare and inject a dose of KESIMPTA and how to properly throw away (dispose of) used KESIMPTA Sensoready® pens or prefilled syringes.

- Use KESIMPTA exactly as your healthcare provider tells you to use it.
- KESIMPTA is given as an injection under your skin (subcutaneous injection), in your thigh or stomach-area (abdomen) by you or a caregiver. A caregiver may also give you an injection of KESIMPTA in your upper outer arm.
- Your healthcare provider will show you how to prepare and inject KESIMPTA the right way before you use it for the first time.
- **Do not** inject into areas where the skin is tender, bruised, red, scaly or hard. Avoid areas with moles, scars or stretch marks.
- The initial dosing is 20 mg of KESIMPTA given by subcutaneous injection at Weeks 0, 1, and 2. There is no injection at Week 3. Starting at Week 4 and then every month, the recommended dose is 20 mg of KESIMPTA administered by subcutaneous injection.

If you miss an injection of KESIMPTA at Week 0, 1, or 2, talk to your healthcare provider. If you miss a monthly injection, give it as soon as possible without waiting until the next scheduled dose. After that, give your KESIMPTA injections a month apart.

What are the possible side effects of KESIMPTA?

KESIMPTA may cause serious side effects, including:

See **"What is the most important information I should know about KESIMPTA?"**

- **Injection-related reactions.** Injection-related reactions is a common side effect of KESIMPTA. Injecting KESIMPTA can cause injection-related reactions that can happen within 24 hours (1 day) following the first injections and with later injections. Talk with your healthcare provider if you have any of these signs and symptoms:
 - **at or near the injection site:** redness of the skin, swelling, itching and pain or
 - **that may happen when certain substances are released in your body:** fever, headache, pain in the muscles, chills, and tiredness.
- **Low immunoglobulins.** KESIMPTA may cause a decrease in some types of antibodies. Your healthcare provider will do blood tests to check your blood immunoglobulin levels.

The most common side effects of KESIMPTA include:

- upper respiratory tract infection, with symptoms such as sore throat and runny nose, and headache. (See **"What is the most important information I should know about KESIMPTA?"**)
- headache

These are not all the possible side effects of KESIMPTA. Call your doctor for medical advice about side effects.

You may report side effects to FDA at 1-800-FDA-1088.

How should I store KESIMPTA?

- Store KESIMPTA in a refrigerator between 36°F to 46°F (2°C to 8°C).
- Keep KESIMPTA in the original carton until ready for use to protect from light.
- If needed, KESIMPTA may be stored for up to 7 days at room temperature, up to 86°F (30°C).
- Write the date taken out of the refrigerator in the space provided on the carton.
- If stored below 86°F (30°C), unused KESIMPTA may be returned to the refrigerator and must be used within the next 7 days. If this KESIMPTA is not used within those 7 days, then discard the medicine.
- Do not freeze KESIMPTA.
- Do not shake KESIMPTA.

Keep KESIMPTA and all medicines out of the reach of children.

General information about the safe and effective use of KESIMPTA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use KESIMPTA for a condition for which it was not prescribed. Do not give KESIMPTA to other people, even if they have the same symptoms that you have. It may harm them.

You can ask your pharmacist or healthcare provider for information about KESIMPTA that is written for health professionals.

What are the ingredients in KESIMPTA?

Active ingredient: ofatumumab

Inactive ingredients: Sensoready pen and prefilled syringe: arginine, disodium edetate, polysorbate 80, sodium acetate trihydrate, sodium chloride, and Water for Injection. Hydrochloric acid may be added.

“MULTIPLE SCLEROSIS *isn't* putting the brakes on our life!”

Dawnia and Harvella are thriving with MS—and together, they're lighting the way for others who are just learning to live with the disease. Here, the tips that work for them and the lessons they love to impart.

—BY JULIE WEINGARDEN DUBIN

“Focus on what you *can* do!”

DAWNIA BAYNES, 43
COMPTON, CA

Dawnia Baynes first started experiencing multiple sclerosis (MS) symptoms in 2004. “My balance was off, and I felt like I was walking to the right,” she says. “I had a hearing test, an EEG and an MRI, but the doctor didn't see anything.”

Then, two years later, her body felt numb from the chest down, and a new series of MRIs showed she had MS. “I was shocked that people could be diagnosed with MS so young,” says Dawnia, who was just 26 at the time. “But I said, ‘OK, what do we need to do now?’ I'm not a ‘woe is me’ kind of person.”

After much trial and error, Dawnia says she's finally found the treatment plan that is managing her symptoms—it includes a biologic (her third), a pill to help with walking and another for spasticity. Although she still has balance issues along with some numbness, tingling and spasticity—“The spasms can make it difficult to lift my leg and walk,

so I'll use a walker or a wheelchair when I'm out”—she says she's felt stable ever since starting her current biologic in the winter of 2019.

What's more, she's busier than ever: In addition to being a long-distance caretaker for her father, who also has MS, Dawnia co-leads two support groups through the National Multiple Sclerosis Society: Youthful Peers Group (YPG) and MS Youngsters. And she also started her own nonprofit, BrightSide365, a support group for people under age 25 with MS to show them they can live a full life.

Try virtual workouts.

“Exercise helps me feel that I'm not giving in to MS, and I see improvements in my body,” says Dawnia, who takes virtual classes that include cardiovascular, strength, balance and stretching work. She's also starting a weekly online dance class.

Continued on p. 18 ▶



“Don't be afraid to live. There's no reason to give up what made you happy before MS!”

Photo by Tomesha Faxio



“I’m on my fifth medication and it’s working. I’m active, and I can walk a couple blocks.”

Find a support system.

“Besides getting encouragement, it’s a great way to learn about things you may not have thought of,” says Dawnia. One example she learned from an MS support group: “Get an MRI when you change medications, so you have a baseline to see if the medicine is working.”

Pace yourself.

“When someone with MS is feeling good, they may push themselves too much and then it affects them for a few days,” says Dawnia. “That’s why I tell my youngsters [who participate in her support groups] to go to that high school football game late, so they have more energy to hang out with friends after.”

Ditch pride!

“Venues will accommodate your needs. I go to Dodgers games, and they pick me up at my car and wheel me to my seat. I know some people want to walk, but why not take advantage of services so you can enjoy the experience more? There are plenty of resources available. Don’t let pride cause you to be sicker.”

Do what you love.

“Don’t be afraid to live. There’s no reason to give up what made you happy before MS. I love music. It makes everything better for me. I have Spotify and Apple music, and I go listen to live music, too.”

“Stay motivated!”

HARVELLA PRINTUP, 51
BELLFLOWER, CA

The first inkling Harvella Printup had that something was awry was way back in 1993, when the then 21-year-old started getting migraines. Around 2011, she had to put away her jogging shoes because her legs felt wobbly. Two

years later, her legs gave way as her date rushed her from the dance floor at a party to the restroom and she fell. That’s when she saw a neurologist, who ran tests, including a spinal tap and MRI, which all came back clear. With symptoms persisting one year later, she saw yet another neurologist who did a cervical spine MRI: “He saw cervical lesions and diagnosed me with MS. I could have been having treatment that whole time.”

Today, Harvella takes a disease-modifying therapy (DMT)—a drug that slows the progression of MS and reduces the number of relapses. She also takes migraine and sleep medicine. “I’m on my fifth DMT medication, and it’s work-

ing. I’m active, and I can walk a couple of blocks.”

Harvella, a full-time legal assistant, co-leads peer and youth support groups with Dawnia Baynes through the National MS Society.

Slow down and meditate.

“I do guided meditation before I go to sleep for about 10 minutes,” says Harvella. “The world gets crazy, and I need to slow it down. My sleep medication doesn’t always work. Meditation calms me and puts my mind at ease.”

Stay cool.

“Your body may shut down when you’re overheated,” warns Harvella, who swears

by a few cooling techniques: “I drink plenty of water, use a cooling towel and put ice packs near me when I work out, and I also make sure not to overexert myself. And when I travel, I hang an ice link (reusable ice cubes you can insert inside a towel; thecoollinks.com) around my neck. Get a hand fan, a cooling vest, or anything to keep your body comfortable.”

Eat foods that work for you.

Harvella favors antioxidant fruits like apples, nectarines and blueberries, which have an anti-inflammatory effect, as well as fish, which is high in omega-3 fatty acids, a nutrient study-proven to improve quality of life for people with MS. On the other hand she stays away from one

culprit: “If I eat too much sugar, I feel lethargic like I don’t want to move!”

Cut tasks down to size.

“Don’t say you’ll clean the house today. Clean one room and do the next another day. If you’re shopping, go to one store per day. Or rest for an hour or two and then shop more later,” recommends Harvella. “I learned that the hard way when I tripped and fell because I was tired.”

Work your brain.

“One of the hardest things I struggle with now is my cognitive function. I know what I want to say, but the words don’t come. I make a list of things I need to do. If I meet someone for the first time, I repeat their name like seven times. I do puzzles, word searches, paint by numbers, and anything to keep my brain active. The brain is a muscle, you need to work it, or it gets weak.” ●

Health  Monitor

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Photo by DeShaun Lavender at ShaunsAngel

How is MS impacting you?

Living with MS can be challenging, but the right treatment can make all the difference. Fill out the assessment below and take it to your next doctor visit, so you and your care team can make sure your treatment plan is the best it can be.



MS interferes with my ability to...	Not at all	A little	Somewhat	A lot	Very much
Work					
Exercise and do other physical activities					
Get a good night's sleep (including trouble falling asleep and staying asleep)					
Concentrate throughout the day because I'm tired					
Engage in relationships with family and friends					
Eat properly and/or pick certain foods					
Go out in public without feeling embarrassed					
Pick out and wear the clothing I like					
Figure out things, like my bills or finding directions					
Meet new people					
Be in a good mood/feel calm and confident					
Be myself around others					
Have a healthy sex life					

Do these statements apply to you?	Never	Rarely	Sometimes	Often	Always
I feel sad or blue.					
I feel nervous, edgy or anxious.					
I feel like everyone is looking at me.					
I say no to activities I'd like to do or try.					



Representation matters As a Black woman with MS, I sometimes struggle to find resources for people like me. I've heard that MS is different for Black people; what can I do to make sure my care fits my needs?

Q

A

Answers to your questions about living with MS

A: The first and most important thing you can do for yourself is to find a physician who you trust and who you believe cares about you and your care. Having a doctor you can talk to means feeling free to ask questions about your diagnosis, your treatments or any issues that arise. It's important to have a culturally competent doctor who sees you as a whole person and not just as your disease.

While it is true that studies have shown MS in Black people is more aggressive, it's not clear if this is due to the disease process itself or if medical disparities also play a role. There is an outdated idea that MS is a "White people disease," so many Black patients are missed early on in their illness, their symptoms dismissed as something else entirely. In addition to being more likely to be diagnosed later in their disease course, Black people are less likely

to get aggressive treatment.

If you or a family member has been diagnosed with MS, I recommend finding a community of other Black patients with MS. Being able to share your stories with other people who have been through it can help you deal with the toll that comes with having MS. One great resource is the National MS Society. They host a Black MS Experience Summit each year, and lectures and discussions are available online through their website, with breakout sessions that act as support groups. They also offer monthly online meetups called Black Voices in Connection where you can meet with people who look like you and are going through the same thing. [See more resources on p. 23]

I also encourage you to join the National African Americans with MS Registry and if you are inclined, to participate in clinical trials. Black

people are underrepresented in MS research, which leaves their needs unaddressed as new treatments are being developed.

Missed meds

Q: Sometimes I forget to take my meds to treat my MS, and I think it's led to relapses in the past. Are there any long-term medication options I could try? Are they safe and effective?

A: The short answer is yes, absolutely. We have come a long way in the treatment of MS, and today there are many options. There are daily injections, monthly infusions, oral pills every six months and everything in between. The options are so vast these days it can be hard to choose which is the right medication for you. Many of these long-term treatments are quite effective and in most cases safe. However, while safety profiles of MS drugs are improving, most treatments still require you to get at least intermittent lab testing to be sure there are no side effects. With adequate monitoring, these new long-term medications can be a game changer for patients. ●



OUR EXPERT: Jessica Baity, MD, board-certified neurologist, Thibodaux Regional Health System, LSU New Orleans School of Medicine.



FIND THE EMOTIONAL CARE YOU NEED



IN-PERSON THERAPY

WHAT IT IS:

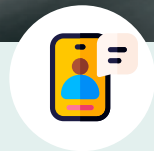
A psychologist, psychiatrist, licensed therapist or social worker can work with you to develop a personalized plan specific to your needs using methods such as psychoanalysis, cognitive behavioral therapy, holistic therapy and more.

IT MIGHT WORK BEST FOR YOU IF:

You're not comfortable speaking up in a crowd, you prefer more personalized attention or you're also looking to work through emotional issues not related to your MS.

HOW TO GET STARTED:

You can find a licensed practitioner who works for you on [psychologytoday.com](https://www.psychologytoday.com) or [goodtherapy.org](https://www.goodtherapy.org).



TELEHEALTH COUNSELING

WHAT IT IS:

The same type of one-on-one session as in-person therapy, but conducted online or via phone or text.

IT MIGHT WORK BEST FOR YOU IF:

You live in a remote area, lack transportation or have mobility issues.

HOW TO GET STARTED:

Visit [teladoc.com](https://www.teladoc.com), an online search engine that can help you get matched with a therapist who fits your lifestyle, or [zocdoc.com](https://www.zocdoc.com), a platform you can use to find a variety of online specialists.



SUPPORT GROUPS

WHAT THEY ARE:

These meetups can sometimes involve people only with multiple sclerosis or people dealing with any type of chronic health condition. They often gather at hospitals, wellness centers, community centers or churches.

THEY MIGHT WORK BEST FOR YOU IF:

You're looking for information or affirmation from others going through a similar situation as you.

HOW TO GET STARTED:

Look for flyers at your local hospital, neurology office or community center, or try searching on [meetup.com](https://www.meetup.com).



JOIN A SOCIAL MEDIA COMMUNITY

WHAT IT IS:

An online peer support group where you can connect with people virtually.

IT MIGHT WORK BEST FOR YOU IF:

You're seeking the same type of support you would get from a support group but want to be able to reach out to anyone at any time. These can also be helpful for those who live in remote areas or who otherwise might have difficulty getting to an in-person meeting.

HOW TO GET STARTED:

Search for "multiple sclerosis support" or [#multiplesclerosis](https://twitter.com/multiplesclerosis) on social media sites like Facebook and Instagram. You can also connect with online support through some of the organizations listed, [right](#).

Resources you can rely on

Looking for places you can trust for information and care? Check these out...

Have more questions about your diagnosis?

- The National Multiple Sclerosis Society (NMSS) [nationalmssociety.org](https://www.nationalmssociety.org)
- Multiple Sclerosis Association of America [mysaa.org](https://www.mysaa.org)
- Multiple Sclerosis Foundation [msfocus.org](https://www.msfocus.org)
- Can Do Multiple Sclerosis [mscando.org](https://www.mscando.org)

Looking for a provider who understands?

- We Are ILL [weareillmatic.com](https://www.weareillmatic.com)
- Clinicians of Color [cliniciansofcolor.org](https://www.cliniciansofcolor.org)

Need help with payment assistance?

- Help Hope Live [helpohpelive.org](https://www.helpohpelive.org)
- The Assistance Fund [tafcares.org](https://www.tafcares.org)
- Needy Meds [needymeds.org](https://www.needymeds.org)
- Medicine Assistance Tool [mat.org](https://www.mat.org)

Looking for an MS podcast or YouTube channel?

- No Stress MS YouTube Channel [@NoStressMS](https://www.youtube.com/@NoStressMS)
- National MS Society YouTube Channel [@nationalmssociety](https://www.youtube.com/@nationalmssociety)
- Real Talk MS Podcast [realtalkms.com](https://www.realtalkms.com)

Looking for support from others with MS?

- The National Multiple Sclerosis Society Facebook Community Group
- The Mighty: Multiple Sclerosis Connections [themighty.com](https://www.themighty.com)
- Multiple Sclerosis Discord Group
- Multiple Sclerosis Reddit Group [reddit.com/r/MultipleSclerosis](https://www.reddit.com/r/MultipleSclerosis)
- The MS Focus Independent Support Group Network [msfocus.org](https://www.msfocus.org)

Looking for transportation services?

- Patient Access Network [panfoundation.org](https://www.panfoundation.org)
- MTM [mtm-inc.net](https://www.mtm-inc.net)
- Centers for Medicare and Medicaid Services [cms.gov](https://www.cms.gov)

Health Monitor Living

Questions to ask at today's visit



Scan this QR code for a free digital copy or home delivery

Do my symptoms indicate MS? What testing do I need to confirm it for sure?



Which treatment do you recommend and why?



If I'm having trouble taking daily medication, are there any long-term options I can try?



What are the risks, benefits and side effects of this treatment?



How will I know if I'm responding to this treatment?



What can I do on my own to avoid MS flares and feel my best?



Can you recommend a support group for people of color, either near my home or online?



On treatment and need help covering the cost?

Ask your healthcare provider about patient assistance programs or call the manufacturer of the treatment you have been prescribed. Many pharmaceutical companies offer copay assistance programs that can make treatment more affordable.