



A PUBLICATION OF THE HENRY FORD CANCER INSTITUTE

# JOURNEY FORWARD



Get Rest,  
Stress Less

Manage  
Financial Toxicity

Cancer and  
COVID-19



## Dear friends,

The COVID-19 pandemic has created an upheaval in all our lives. And while you are likely feeling a range of emotions – please know that you are not alone. Your Henry Ford Cancer Institute team is working tirelessly, behind the scenes, during your treatment, night and day, to keep you safe and provide the support you need to continue your fight.

From day one, our team of experts put into place additional safety precautions for those who are in active treatment – and remains steadfast in their commitment to provide you and newly diagnosed patients with the safest, most advanced cancer care. We'll meet you where you're most comfortable, so you never have to miss an appointment – whether it's a virtual care visit or in-person appointment at one of our locations.

In this issue of *Journey Forward*, you will find resources to help you and your family navigate this new “normal.” Learn about more restful sleep, tips from our financial counselors and details about our OncoSTAT clinic (more on page 4), which assists patients undergoing chemotherapy and/or radiation therapy, and those who may be experiencing COVID-19 symptoms.

While we've postponed the opening of our new Brigitte Harris Cancer Pavilion in Detroit until later this year (more on page 10), we remain focused on the theme of Illuminating Hope for this transformative “hub” for our cancer services across Michigan. This theme is so appropriate, now more than ever, as we celebrate each of you – our champions of hope!

Onward and upward,

**Steven N. Kalkanis, M.D.**

CEO, Henry Ford Medical Group

Senior Vice President and Chief Academic Officer,  
Henry Ford Health System

Medical Director, Henry Ford Cancer Institute

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### ON THE COVER

After an oropharyngeal cancer diagnosis, veteran radio broadcaster Al Randall Higgins makes the ultimate save – his voice.

*Read the full story on page 6.*



Tom Mikkelsen, M.D., medical director of Henry Ford's Precision Medicine program, was part of the team that treated Chris' father more than a decade ago.

## \$25 Million Gift for Precision Medicine

Chris and Lisa Jeffries have donated \$25 million to accelerate the growth of Henry Ford's Precision Medicine program, which has been at the forefront of innovating world-class, targeted cancer treatments. Both have lost a family member to brain cancer. Chris' father outlived his prognosis by five years, in large part due to clinical innovations and comprehensive treatment at Henry Ford.

## First-in-Human Clinical Trial for HPV Cancers

Henry Ford is the only cancer institute in Michigan enrolling patients with human papillomavirus-related cancers (HPV-16+) for a first-in-human, phase 1 clinical trial. The unique treatment, called Hookipa H-200-001, involves a genetically engineered HPV-related viral vaccine, HB-201, and another immunotherapy agent, Opdivo. The therapy targets recurrent or metastatic carcinoma of the head and neck, gynecological malignancies or anal cancer. It has been shown in animals to destroy cancer cells.

## Non-Invasive Alternative to PSA Test

A prostate cancer biomarker in the urine may improve detection of certain prostate cancers, according to a study published by Henry Ford researchers. The current screening method for prostate cancer is the prostate specific antigen (PSA) blood test. However, it sometimes shows false-positive results, leading to unnecessary prostate biopsies and the risk of bleeding and infection. The discovery of this unique biomarker may offer another non-invasive detection test for prostate cancer.

## Improving Breast Reconstruction Rates for Underserved Women

Henry Ford has achieved the highest published rate for breast reconstruction in underserved African American women and working low-income women in the United States. A recent Henry Ford study shows a 20 percent increase in breast reconstruction rates among underserved patients. Researchers attribute the increase to educating and providing patients with opportunities for immediate reconstruction consultations at their first appointment with Henry Ford's breast cancer team, which includes plastic surgeons.

## COVID-19 AND CANCER:

# Your Questions Answered

*Coronavirus (COVID-19) has impacted every aspect of our lives and has presented unique challenges to cancer patients with weakened immune systems, as well as those currently in treatment or on a survivorship care plan. It's normal to have concerns. Here are some answers and resources that can help.*

### AM I MORE LIKELY TO CATCH COVID-19 IF I HAVE CANCER?

COVID-19 is a highly contagious respiratory virus. Having cancer makes you more susceptible to a serious illness like COVID-19. Chemotherapy, radiation therapy and transplant therapy weaken the immune system. However, cancer survivors who completed treatment two years ago will likely have stronger immune systems.

### WHAT CAN I DO TO PREVENT MYSELF FROM CATCHING THE VIRUS?

- Avoid public places.
- Stay six feet away from other people.
- Wear a mask.
- Wash your hands frequently with soap and water

- Avoid touching your face, mouth, nose or eyes with unwashed hands.
- Clean and disinfect surfaces frequently.
- Use the phone and video chats to stay connected with friends and loved ones.

### WHAT SHOULD I DO IF I EXPERIENCE COVID-19 SYMPTOMS?

If you are experiencing COVID-19 symptoms – fever, cough, congestion, sore throat, runny nose, muscle aches and pains or shortness of breath – call your oncologist or our OncoSTAT urgent care clinic weekdays, 8 a.m. – 5 p.m. at (313) 916-9840. We will help you quickly schedule a COVID-19 test.

### SHOULD I KEEP MY APPOINTMENTS FOR CANCER TREATMENTS OR FOLLOW-UP SCANS?

Yes. If you are scheduled for an appointment, it's important to talk with your oncologist about the benefits and risks of continuing or delaying treatments or routine scans.

### ARE VIRTUAL CARE OPTIONS AVAILABLE?

We understand you may be hesitant to visit a hospital or clinic during this public health emergency. Our physicians will meet you where you're most comfortable. Newly diagnosed and current patients can schedule virtual visits or in-person appointments at our Southeast or South Central Michigan locations. Dietitians, psych-oncologists and several support services are temporarily doing phone or video calls.

Get the latest information about COVID-19 and cancer: [henryford.com/CovidSupport](https://henryford.com/CovidSupport).



## ASK DR. RYAN

# How to sleep, sweet sleep

*Michael Ryan, Psy.D., is the clinical director of cancer support services at the Henry Ford Cancer Institute.*

Cancer can seem like a bad daydream, causing insomnia in exhausted people. About 50 percent of cancer patients experience sleep disturbances triggered by a combination of factors. Medications such as steroids and chemotherapy can be sleep stealers. Stress, unemployment and lifestyle changes due to the COVID-19 pandemic are also culprits.

### COMMON CAUSES FOR CANCER-RELATED INSOMNIA

Pain from cancer or treatment can interfere with sleep. Take your pain meds, do deep-breathing, start relaxation therapies and engage in other healthy distractions. Discuss medication issues with your care team.

Without a normal work routine, patients or survivors may have sleepless nights. Keep a daily schedule. Include daily exercise and relaxing evening activities.

Electronic devices, anxiety and discussions about money can be overstimulating. Turn off electronics at 8 p.m. Postpone money talks until morning. Exercise, meditation, deep-breathing, journaling, yoga or prayer can combat stress and facilitate sleep.

Some foods can make you uncomfortable at bedtime. Avoid white bread, rice, pasta and

sugary snacks. Eat smaller meals. Pass on the caffeine and alcohol – try milk or herbal tea instead.

### THE GREAT NAP DEBATE

Daytime grogginess caused by nighttime sleeplessness is tricky. Try napping. Or not.

- **Short power naps** lasting not more than 20 minutes can fully restore cognitive function according to NASA researchers. Try it.
- **Long healing naps** of three hours may be required for patients fatigued by cancer or treatment. If insomnia occurs, reduce naptime.
- **Avoidance naps or procrastination naps** may be a sign of depression or coping difficulty. Plan to engage in activities to combat depressive symptoms and consider professional help.
- **No naps** may be the best option for some people. Experiment to see what works for you.

### SWEET DREAMS, EVENTUALLY

If you're still having trouble sleeping, keep a sleep journal to accurately record facts to use when talking to your care team. Undiagnosed sleep apnea or other problems might be the culprit.

# Voice of Survivorship

*In breakout play against cancer, veteran hockey broadcaster makes ultimate save: his voice.*

*Sitting in a swimming pool in Florida in 2017, Al Randall Higgins was doing what most radio announcers might do while taking a winter break – they check the neck for infections like strep throat. If they feel swollen lymph nodes, they make a mad dash for a Z-pack of antibiotics.*

The first round didn't work. The second round didn't work. The doctor sent a camera down Al's throat for a better look. Then he took a deep breath and told Al – who had been the radio voice of Michigan hockey for 25 years – that a biopsy would determine if he had oropharyngeal cancer.

He had it. And it had metastasized from the base of the tongue to a lymph node in his neck.

The goal: kill the cancer, save the voice.

Al was referred to the Henry Ford Cancer Institute, where his doctor's colleague from the University of Johns Hopkins Medical School was now the internationally known Director of the Head and Neck Program, Steven S. Chang, M.D.

Surgery wasn't a good option for Al. "He wanted to make sure there was no risk for any changes to his voice, accent or intonation," Dr. Chang says. "Even though this was a very surgically amenable cancer, we tailored the treatment to his lifestyle and needs, empowering the patient in the decision-making process."

Prior to treatment, Al met with radiation oncologist Farzan Siddiqui, M.D., Ph.D., and a team comprised of a speech and swallow specialist, dietitian and psychologist. Early and extensive support was available through Henry Ford's survivorship clinic.

The tumor wouldn't be removed surgically. Instead, it would be irradiated in 35 treatments using intensity modulated radiation therapy to avoid damage to his voice box. He also would receive three rounds of chemotherapy.

But first things first: Al wanted to postpone treatment until the hockey season ended.

Seven weeks later, his wife Cindy and his friends began a rotation on the "Al Express," driving each weekday from Dewitt (north of Lansing) to Henry Ford Hospital in Detroit – 202 miles round trip.

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“  
You’ll get knocked  
down, but you  
have to get up.”

— AL RANDALL HIGGINS



“The treatment was the hardest thing I’ve ever done in my life,” Al says. Most of the side effects happened within a month after treatment: no saliva, no taste, no ability to talk or eat or swallow. Sleeping was tough. A recliner chair became his bed. Eventually, medicinal cocktails numbed his throat, and he was finally able to get some food down.

Taste usually returns three months after radiation, and dry mouth often reverses within a year, Dr. Siddiqui says.

“They warn you that the side effects can be a nightmare,” Al says. Weakened by dehydration, lack of food and sleep, he wanted to give up. “I had to tell myself to keep going. I needed a lot of support. Without my wife Cindy, my faith and my family, I would have never made it.”

“Eventually you feel a little better. Then a little more. Then all of a sudden, you’re a heck of a lot better,” Al says. “Finally, you’re looking at the experience in your rearview mirror.” In December 2019, he had his sixth clean scan for a cancer that has an 85-90 percent survival rate.

Al advises patients to listen to their doctors. He admits he didn’t take the prescribed medicinal cocktails so he could eat. “I didn’t pay attention to details. I suffered,” he says.

“I’ve always been a fighter. My parents molded me to take a punch and keep going. You’ll get knocked down, but you have to get up,” Al says. When he’s not calling hockey games for the University of Michigan, he doubles as the co-owner of a windshield glass business in Lansing.

To fighters, survivors and their caregivers, he says, “we’re all pretty strong. Everybody has that extra something in them that will come out when they need it. Keep pushing yourself every day. If you pray to be strong, you will be stronger. Stay close to friends and family.

“Living through the cancer is one thing, but living *after* cancer is another thing. I want to live to help other people. You have to find your purpose in life,” says Al, who volunteers to drive cancer patients to their appointments.

For the University of Michigan, Al called games in the 2019-2020 hockey season using the same voice he’s had all his life – but with a heck of a lot more gratitude.



Learn more about Al’s story and watch his video at [henryford.com/JourneyMagazine](https://henryford.com/JourneyMagazine).

## Nudge Caregivers to Rest

*It’s usually the caregivers who prompt patients to rest.  
But there are good reasons to switch roles.*

Caregivers are so busy taking care of the patient, they often forget to take care of their own needs, says Cyndy Ulreich, a certified oncology nurse practitioner at the Henry Ford Cancer Institute. “I don’t think caregivers understand how much the patient or survivor wants them to take care of themselves,” she says. “Patients want their caregivers to have a good life. They feel better knowing their caregivers are caring for themselves.”

### PHYSICAL AND EMOTIONAL ISSUES

Caregivers have been known to suffer with undiagnosed or uncontrolled health conditions such as diabetes. During stressful times or unusual world events, many people may lose perspective, feel anxious or cry more easily. Others get aggressive and demanding. Anxiety can raise stress chemicals, increasing blood pressure, muscle tension and pain perception. It can take a lot of energy to calm caregivers, Cyndy says. Worse, if a patient feels suffocated by doting or overbearing caregivers, that can slow the healing process.

### KINDNESS IS KEY

Kindness can reduce stress levels and increase a sense of well-being. Kindness – given and received – endears caregivers to patients. “I’ve seen decreased stress in people who encourage their caregivers to practice self-care,” says Cyndy, who has been a cancer caregiver for her own family members.

Give caregivers a nudge to rest or take time for self-care, especially during your cancer treatments. Show gratitude. A pat on the hand, a look in the eye, a word of encouragement from the patient – it all helps. “Tell your caregivers, ‘I know this is hard on you, too. I appreciate everything you’re doing for me,’” Cyndy says.

Find more resources for caregivers at [henryford.com/CancerSupport](https://henryford.com/CancerSupport).



### Rough flight with cancer? Caregiver, first put on your oxygen mask.

To avoid feeling “caregiver burnout,” try doing the following:

**INCREASE STRENGTH, CONFIDENCE AND PEACE.** Try yoga, dancing, drawing, listening to music, telling jokes, singing, praying, journaling, eating veggies, drinking more water, getting massages, taking *your* medicine or smiling anyway.

**SAY “YES” TO FRIENDS AND FAMILY.** Accept offers for help and visits. During visits, excuse yourself for a short walk or time alone.

**CONNECT!** Get advice from others in support networks, ask questions and express your feelings. They’re on the same survival route.



## Brigitte Harris Cancer Pavilion: Illuminating Hope

*Transformative care. First-in-world breakthroughs. Precise cancer treatments. Most of all – illuminating hope for patients locally and worldwide.*

### DESTINATION FOR HEALING INNOVATION

Our new Brigitte Harris Cancer Pavilion embodies an innovative healing environment that matches the heart and soul of Detroit with the world-class care provided by Henry Ford Cancer Institute experts.

The Pavilion encompasses 187,000 square feet, six floors and the Nancy Vlasic Skywalk connection across West Grand Boulevard to Henry Ford Hospital. It has been designed to create a truly seamless experience for each person's unique cancer journey.

While the Pavilion opening will be scheduled for a new date later in 2020, instead of the originally planned July 21 date, our team remains committed to this new Pavilion as a destination for healing innovation that will transform cancer care.

Get the latest updates on our cancer pavilion's progress and opening date: [henryford.com/NewCancerPavilion](https://henryford.com/NewCancerPavilion).



### SURVIVOR SPEAKS OUT:

## Attitude Adjustment

Dan Roth was a 6'3", athletic dad and loving husband of a college instructor. At work, he played with words while writing commercials. Good natured, he joked with his doctors just before learning he had colon cancer. Henry Ford surgeon Eric Szilagy, M.D., removed the tumor and learned it had metastasized to his lymph nodes. Chemotherapy was the next step. But that step would change the way Dan walked.

As soon as the chemotherapy started, he had a reaction – chemotherapy-induced peripheral neuropathy (CIPN). First, there was tingling. Soon he lost all feeling in his feet and hands.

"Normally, I'm a very easygoing person. Almost overnight, I transformed into a cranky, irritable, emotional and mean person," says 45-year-old Dan, who began walking with a cane. "I lost myself in the treatment. I completely lost sight of how my journey was impacting those closest to me."

His wife and dad each had a blunt conversation with him. He then made the choice to change.

Dan acted in ways that were the *opposite* of the anger and depression he felt. One good choice led to another.

And it all started when he:

- Smiled at the patient next to him in the infusion room
- Joked and suggested a game of hide and seek
- Acted kindly to other patients
- Focused on the bright side – chemotherapy was killing cancer cells
- Learned to adjust and cope over time
- Rediscovered hope
- Spread hope to other patients and his loved ones

Two years later, Dan's scans are cancer free, and the CIPN has improved a bit. Now Dan's playing baseball with his kids and writing novels. He recently finished a witty and rhythmic kid's book – *Gargánash and His Talking Mustache* – about a man who is mean but chooses to act with kindness and follow the golden rule.

Through his choices, the character recovers and rediscovers himself. Just like Dan.

Learn more about Dan's story and treatment: [henryford.com/JourneyForward](https://henryford.com/JourneyForward).



CARE IT FORWARD

# Game On Cancer

HAVE FUN WHILE MAKING A DIFFERENCE FOR CANCER PATIENTS AND FAMILIES

A cancer diagnosis is not only emotionally difficult, but it can also take a toll on a family's finances. Henry Ford Health System's Game On Cancer, in partnership with the Detroit Lions and the Detroit Pistons, raises money to alleviate barriers that cancer patients face on their road to recovery and funds research to find a cure.

Now in its sixth year, Game On Cancer has helped more than 10,000 cancer patients. It has helped patients get to and from their medical appointments, keep the lights and heat on in their homes, and paid for important prescriptions. Game on Cancer also has in the past sponsored innovative cancer research, important complementary therapies (such as acupuncture, massage and exercise) and survivorship groups, ensuring that all cancer patients have the support they need in their cancer journeys.

This year, Game On Cancer is recruiting new members for its survivor team Tougher Together. Teammates have fun raising money to support each other and cancer patients.

Join the Tougher Together team and learn more at [GameOnCancer.com](http://GameOnCancer.com).



Many cancer patients were unable to leave their homes during the COVID-19 public health emergency, making it difficult to obtain healthy foods. So, volunteers from Game On Cancer and our cancer support services hit the road, delivering weekly meals – and a sense of comfort – to more than 100 of our cancer patients. The donated meals were made possible in large part by Game On Cancer's support from Kroger Co. of Michigan.

## Join Our Survivorship Group on Facebook

When you join our Survivorship Group on Facebook, you'll have the opportunity to connect with nearly 500 Henry Ford Cancer Institute patients, post-treatment survivors, caregivers and family members who have walked in your shoes.

Our Facebook group is a place where members can find support and comfort. They can interact and share important resources to help navigate this unique journey.

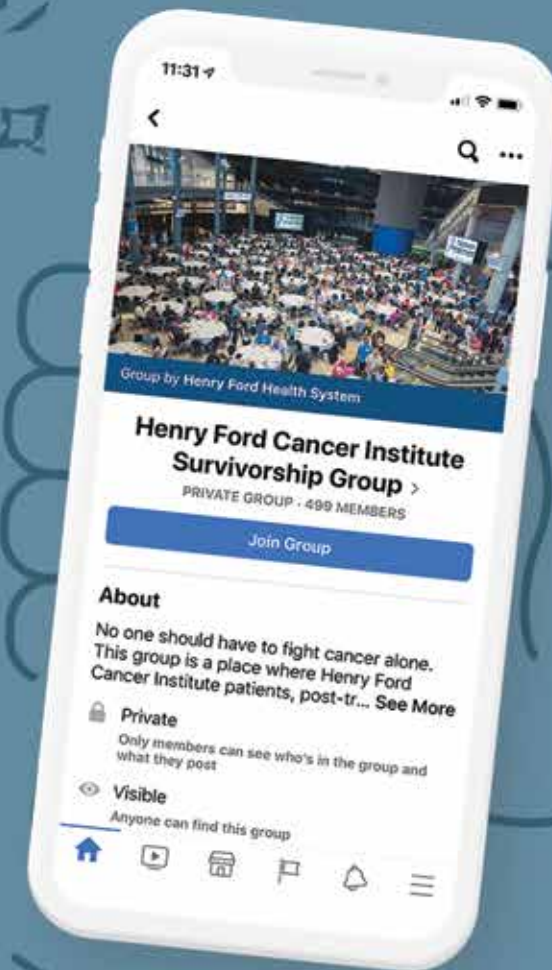
### EDUCATIONAL CLASSES FROM THE COMFORT OF YOUR HOME

We've added a new feature to our Facebook group: streaming classes via Facebook Live video. Now members of our Facebook group can interact with experts at Henry Ford Cancer Institute as they present topics important to your health and well-being. Watch for posts in the group about upcoming topics on Facebook Live!

### HOW TO BECOME A MEMBER

If you have a Facebook account, it's easy to become a member of the Henry Ford Cancer Institute Survivorship Group.

- Go to Facebook.com and enter your login information.
- Using the search field at the top of the page, type "Henry Ford Cancer Institute."
- Click on the Henry Ford Cancer Institute Survivorship Group.
- Request to become a member and answer a few questions. *(Note: You must answer these questions to be admitted to the group.)*
- Get connected to fellow warriors and start sharing!



# Respite from Financial Toxicity

*Medical bills can feel toxic, but so can unemployment and anxiety about world events. “We don’t want financial stress impacting patients’ health, and we do a good job of stopping stress before it gets out of control,” says Jennifer Bargas, CPhT, a financial counselor at the Henry Ford Cancer Institute.*

## HOW CANCER FINANCIAL COUNSELORS CAN HELP

When patients receive a cancer diagnosis, nurse navigators can connect them to financial counselors. But it’s important for patients to make their financial arrangements *before* treatment begins.

The financial counselor determines a patient’s eligibility for financial aid through Medicare, Medicaid, drug companies, insurance companies and cancer foundations – and makes connections to the appropriate resources. Additionally, social workers provide information about disability, employee rights, work accommodations, medical leave and budgeting.

“Once a patient gets into our system, things move quickly. We try to help before a catastrophic event happens,” Jennifer says, noting that financial concerns have led some cancer patients to cancel appointments or even stop treatment.

Certain cancer drugs can cost \$90,000 per treatment, leaving patients with co-payments of \$18,000. When patients see that their debt of \$18,000 can be reduced to \$6.93, it gives them hope, Jennifer says.

## FINANCIAL HELP AFTER TREATMENT

Getting financial assistance after treatment can be difficult. Most cancer foundations and drug companies have a “lookback” period of one to six months to pay claims, Jennifer says. If a patient enrolls today, and the lookback period is six months, claims will be paid six months prior to the enrollment date. Counselors determine if any payment opportunities exist and immediately submit the paperwork.

Another option is to enroll in the Henry Ford Patient Financial Assistance Program. Patients who have had surgery or radiation at Henry Ford may qualify for help through this program. They can obtain the enrollment paperwork from financial counselors, social workers or the billing department. Processing takes about two weeks.

If unexpected financial circumstances occur, financial counselors can help you arrange a payment schedule.

*Connect with a financial counselor and learn more: [henryford.com/CancerSupport](http://henryford.com/CancerSupport).*



# Resources for Patients and Caregivers

We offer patients and caregivers access to extensive resources, including Henry Ford cancer support specialists, to help throughout their cancer journey. This page provides a snapshot of those resources. See our complete list at [henryford.com/CancerSupport](http://henryford.com/CancerSupport).

## FINANCIAL PLANNING AND ASSISTANCE

- **Billing and Cost Estimates** – Offers guidance on your financial responsibilities, as well as estimates based on your expected services and your specific insurance co-pay, co-insurance and deductible information: [henryford.com/Billing](http://henryford.com/Billing)
- **Patient Financial Assistance Program** – Provides patients with fair pricing of Henry Ford medical services and assistance to find options for managing medical costs: [henryford.com/Billing](http://henryford.com/Billing)

## PRESCRIPTION REFILLS AND DELIVERY

- **Free Home Delivery for Prescriptions** – Offers free delivery for cancer patients’ medications through Pharmacy Advantage. Most insurance plans are accepted: [PharmacyAdvantageRx.com](http://PharmacyAdvantageRx.com) or (800) 456-2112
- **Henry Ford Rx App for Your Phone or Tablet** – Allows prescription refills, tracks refill status, finds nearby stores to place a refill request and sets dosage reminders: Download for free from the App Store or Google Play

## GRIEF SUPPORT

### HENRY FORD HOSPICE

Provides grief support for adults and children, and a bereavement specialist for at least 13 months for family members of Henry Ford patients: (586) 276-9570

### SANDCASTLES

Offers support for children affected by a loved one’s death: [henryford.com/Sandcastles](http://henryford.com/Sandcastles)





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# 6 Tips for Overcoming Stress



### *Stick to a schedule*

Maintain the same sleep and wake times every day.



### *Take a nap*

Rest before 2 p.m. every day for 20 minutes or less.



### *Practice good sleep hygiene*

Wind down an hour before bedtime – dim lights, put away electronic devices, take a bath, etc.



### *Get moving*

Exercise regularly to sleep more soundly.



### *Bathe in the light*

Wake up your body with natural sunlight.



### *Take steps to de-stress*

Use meditation, deep-breathing or other relaxation techniques.

**JOURNEY FORWARD – SPRING 2020**

