

# Living **now**

A guide to life after transplant

Issue 6: 2 years & beyond



Recovering a  
sense of purpose



On the cover: Rob, transplant recipient

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## Welcome to *Living Now*

**This newsletter is the sixth of six issues** produced by Be The Match® patient services. Each issue addresses various aspects of life after transplant, from three months post transplant, to two years and beyond. Every person's experience is unique. This is not a timeline against which to measure yourself. This collection of observations, tips and resources is designed to help you make the most of living now.

Be The Match offers free educational resources, confidential one-on-one support and financial guidance to support patients, families and caregivers, before, during and after transplant. We can help you learn more about transplant as a treatment option, plan for a transplant and learn what to expect after transplant.

Note: Information in this newsletter is based on input from marrow and cord blood transplant experts and represents general principles and recommendations. This information is not intended to replace, and should not replace, your doctor's medical judgment or advice. Always consult your own medical team regarding your specific situation.

### Information for caregivers

A special caregiver issue of *Living Now* is available for spouses, partners, parents or anyone else who helps care for a loved one after transplant. It includes valuable information and resources on self-care, getting help from family and friends, finding emotional support and more. If you have not received a copy, you may order it online from [BeTheMatch.org/patient](http://BeTheMatch.org/patient) (click on Order Materials), or by calling 1 (888) 999-6743. Caregiving information is also available online at [BeTheMatch.org/patient](http://BeTheMatch.org/patient) (click on Caregiving).

### To unsubscribe

We make every effort to keep our mailing list current. If you have received this newsletter in error, or do not wish to receive future issues, you may unsubscribe by calling 1 (888) 999-6743 or e-mailing [patientinfo@nmdp.org](mailto:patientinfo@nmdp.org).

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## ► Reflections on the transplant journey

# Moving from “surviving” to “living”

**A**t two years post-transplant, you may be reflecting on how your transplant journey has changed you or your plans for the future. Emotional, psychological and spiritual changes can be just as real as the physical changes you’ve been through. Recovering your sense of who you are and how you will live your life going forward are important aspects of your overall recovery.

In their book, “Picking Up the Pieces – Moving Forward After Surviving Cancer,” Sherri Magee, Ph.D., and Kathy Scalzo, M.S.O.D., present a four-phase approach for transitioning from surviving to living well. These are: 1) The Inquiry phase, recovering a sense of self, 2) Discovery phase, recovering a sense of control, 3) The Growth phase, recovering a sense of meaning, and 4) Reflection phase, recovering a sense of the future.

The authors describe the four phases as being like the corner pieces of a jigsaw puzzle. Understanding these aspects of your experience help explain how other parts of your recovery fit together to make a complete picture.

In this issue, four people who received transplants share their own stories to illustrate these phases of recovery. ■

“

My experience broke me down, but it also built me back up. When I think of everything we survivors have been through, I realize that we are amazing! We are rock stars!”

—**Kristina, transplant recipient**



Kristina, transplant recipient

# Recovering a sense of self



Kristina, transplant recipient

## Kristina's philosophy: There is life after transplant!

From a sailboat in Puget Sound to the confines of a hospital bed; from stomping through the jungles of Cambodia to receiving chemotherapy. Kristina defined herself by her zest for adventure and travel. In 2007, she was diagnosed with myelodysplastic syndrome (MDS), a rare disease that was discovered by a fluke, with no symptoms. Her disease rapidly turned into acute myelogenous leukemia (AML) and doctors told her she urgently needed a transplant. Luckily, Kristina found a matching donor and received a transplant soon after diagnosis. But as she would discover, this was merely the beginning of recovering her fiercely-independent sense of self and an active, passionate lifestyle.

**C**ancer wasn't ever supposed to happen to me. I was attracted to living life on the edge and suddenly, I was told I was dying. Did they know who they were talking to? Maybe it was the New Yorker in me, but there was no way this was getting me down.

Going into treatment, I knew I would not be able to be the individual I have always been or lead the lifestyle I was so passionate about. I knew I had to accept the transition and take my recovery one day at a time. Simplifying my perspective helped me make it through that time in my life. Just as I had packed my backpack for countless trips, I decided to pack my emotional backpack and get through it. The sun will always rise again in the morning and set the next day.

After transplant, the biggest thing for me was getting back my quality of life. I knew I would get there no matter what. Though my recovery went well, I had a flare-up that was a devastating setback. I experienced graft-versus-host disease (GVHD) and spent so much time on the couch watching TV that it scared me. It made me realize how easy it was to curl up in a ball every day, how easy it would be to slip into feelings of self-pity.

As post-transplant survivors, we have to drag ourselves out of it. It took a lot of self motivation. The initial step of recovery is to just get moving. It sounds cliché to say, "just get up," but it's true. Whether you do this alone, with a caregiver or through a program, little steps make a big impact.

I joined Team Survivor Northwest and attended every class to help regain my quality of life. I was determined to cross-country ski at day 83 post-transplant – while still being attached to IVs. I succeeded in getting stronger and bonding with other women whose lives were affected by cancer.

My "new normal" included my mindset, physical changes, how people reacted to me and my emotional well-being. And while I experienced many changes and realized new things about myself, I was able to get back the part of my life that I loved.

It's amazing to live through such an experience. Look at what we, as survivors, have done already! If we can beat a disease, we can get through the recovery as well. ■

### Your sense of self

You may feel as if you are balancing the life and person you know now and who you were before your disease. Think about the emotional, physical, spiritual and social changes you have experienced and use these changes to assess your sense of self. Ask:

- In what ways have I remained the same, and in what ways have I become someone new?
- What have I gained and what have I lost through my experience?
- How do I pick up some of the pieces of my life and leave others behind?

# Recovering a sense of control



Esther, transplant recipient, with her daughters

## Esther's journey: Never have a BAD day.

Esther was diagnosed with aplastic anemia (AA) in 1996 when she was 24 years old. In 1998 she became transfusion dependent. She managed her AA like a chronic disease until late 2006 when her condition suddenly worsened. She received her transplant in 2007.

**T**he transplant caused major upheavals in our lives. My husband, my oldest daughter, who was just 2 ½, and I permanently relocated from Washington, D.C., to Boston for my transplant. It was hard to leave our friends and old life behind, but keeping the family together was the best solution for us, financially and emotionally. We lived with my in-laws for nine months while we searched for a home of our own.

I've been a very active and engaged patient, doing research, asking lots of questions, following doctor's orders and doing whatever I could to support my recovery. My number one goal was to get well. I didn't always like the path I was on, with all the ups and downs, but I stayed the course and always did the best I could.

During the first year after my transplant, I experienced typical side effects: hair loss, skin and mouth irritation, food aversions, nausea and acute GVHD of the gut. There have been times that were frustrating and disappointing. But whenever I started to complain, my husband would remind me of the promise I made on the day of my transplant: that we don't have bad days. We may have sad days, scary days, disappointing days or feeling unwell days, but never a BAD day.

I couldn't always control my physical condition, but I could control my attitude. I think that played a big part in my recovery. Focusing on my priorities put things in perspective and kept me motivated. For instance, there were days when I thought that getting through it would be easier if I wasn't a mom, but the truth was it was exactly

the motivation I needed to get up, get dressed, exercise and take medications that made me nauseated.

As I rebuild my life, I realize that my experience changed me. I am more grateful and I tell people what they mean to me more often. In some ways, I'm a nicer person, more compassionate and less judgmental. But in other ways, I have less patience for nonsense, complaining and ingratitude. I'm also more confident now. I live more fully and authentically, recognizing that life can end at any time. What we make of it is up to us.

Things are not what they were before. Some things are worse, but most are different and better. The key was letting go of what I had before so I was open to loving my new life. Clinging to what I used to do, or look like or feel like was keeping me trapped in the past. I had to mourn it so I could embrace what I have today. It's not about pretending, but about letting myself be sad for a period of time and then getting over it and moving on.

So I can't take my kids to the pool, but I can take them to the museum. I can't ride bikes with them and my husband, but I can do scrapbooking with them and help out in their classes at school. For every limit, I create an alternative that meets the same needs for togetherness and fun.

Today, life is good. Not always easy, but good. I open my eyes, think of my donor, and know that I am here. I walk into my daughters' room and know how lucky I am. After all we have been through as a family, we are not only surviving, but thriving! ■



When I look back, I think of how I was sick for a while, almost died one very scary night and got a transplant when there were only days left on the clock. I lived through the first day, and I lived through the second day, and I kept on living until I stopped counting the days. Then I stopped counting the months. I look forward to a time when I no longer count the years.”

—Esther, transplant recipient

### Your sense of control

Making a new life and achieving new goals takes focus and determination. You may have to give up old habits and old ways of thinking. Defining what you want can help you move in a new direction. Ask:

- How can I become an active participant in my recovery?
- What are possible risks in my life?
- Am I living the life I want to live?
- What is my vision of living well?

# Recovering a sense of meaning



Nicole, transplant recipient

## Nicole's philosophy: Love stronger, care more, play harder.

Nicole found out in November 2004 that a transplant was critical to her survival. She was not responding well to chemotherapy and was experiencing organ failure. A month later, Nicole found a matching donor for transplant. Her time leading up to transplant was not easy. Nicole was lucky if she had four or five days out of the hospital from diagnosis until transplant, and at one point, weighed only 72 pounds.

**A**s a 24-year-old, it was tough to date while being bald. I was young and hung up on superficial aspects of life, until I decided to stop worrying about what other people thought and love myself for who I was. I never bought a wig; it felt empowering to go bald and not try to gain acceptance or approval from anyone. It made me appreciate life more.

After transplant, I set mini-milestones to stay focused on getting my energy back. From getting winded and being in a wheelchair to being able to lift small weights and go for walks; I gradually got back to living life! I was doing the things I did before, but with a greater purpose. As individuals, we empower our bodies to recover and get stronger. With the support of my friends and family, I would look forward to small pleasures like walking on the beach. Staying focused on the future and continuing to plan for tomorrow helped.

I went to a wellness center to help with my recovery. I was always very independent, so I was reluctant at first, but the people there helped me challenge myself and move forward. The support I received from my family and friends, made me realize it's all about those who surround you. As people, we are here to help each other.

I am grateful that I found a matching donor so I could receive my transplant. I have gotten to know my donor, and

I am in awe every day that I am here because of someone else. It made me think about how important it is for people to be on the Be The Match® registry—that someone out there could be that one person for someone else.

Making it through a tough time inspires me to live each day in the moment.

When I do something, I give it my all. I went back to college three months after returning home from the hospital. I am passionate about volunteering and spreading the word about transplant. I visited a cancer center and brought blankets for patients. Being an example of hope for other patients is what I love about survivorship.

Getting this far was not always easy. I struggled with finances during treatment and often dreaded looking at my bills. I was young during my transplant and wanted to be out doing things. I had to stay focused, take small steps and not let struggles get in the way of my progress.

Today, I am determined to make the best of my experience. My goal is to help other patients like me get the chance to experience life with a new perspective. Even though I am very strong and healthy today, I still hold onto every second of life and take advantage of every opportunity that comes my way. ■



Being an example of hope for other patients is what I love about survivorship.”

—Nicole, transplant recipient

### Your sense of meaning

No matter how you may have felt about your transplant experience, it is valuable to find insight and perspective from your journey. While it may be difficult, developing a vision for the future and a deeper meaning beyond the disease will carry you far into your life after transplant. Ask:

- What new insights have I gleaned from this experience? In what ways have they made me stronger?
- How have my priorities changed?
- What new clarity does my life have now?

Recovering a sense of

# future



Rob, transplant recipient, with his family

## Robert's story: My children are my future.

As a lieutenant in the NYC Fire Department who responded to the 9/11 attacks on the World Trade Center, Robert understands crisis. But rescuing others did not prepare him for the challenges he was about to experience. Robert received a transplant for myelodysplastic syndrome (MDS) in September 2005. Forced into early retirement as a result of his physical limitations, Robert has had to redefine how he sees himself and what he wants for his future.

**A**fter the transplant, I experienced acute and chronic GVHD, and I'm still dealing with GVHD of the skin as well as weight gain and mood swings from steroids. I struggle with fatigue and problems with memory and concentration. The hardest part is not being able to keep commitments because I never know how I'll feel from one day to the next. It makes it hard to accomplish the tasks I set for myself.

On the positive side, I'm still getting better. I'm still learning my physical limitations, and some times I exceed them, but day by day, I am able to do more and that encourages me to keep trying.

My level of fear about getting sick has also decreased. I don't need blood transfusions anymore and I don't worry about blood tests. And even though I miss working, it's a relief to not have to worry about returning to work and wondering if I'd be able to perform my duties.

I'm grateful for all the help my family has received, especially for all the rides and meals from my coworkers at Engine 151 and Ladder 76, and from my wife's coworkers at Stanton Island University Hospital. And of course, my doctors and nurses, and all the individuals and organizations who provided both financial and emotional support.

And then there's my donor. I was eager to thank him from the start, but because of confidentiality, it took a long

time, and I didn't know if he'd received my cards or not. That was frustrating, but we finally got in touch with each other, and he's a great guy.

There was never really a time when I didn't look to the future. I worked toward short-term goals, like getting my central line removed, controlling my GVHD, and being able to quit taking steroids.

Today, my three children provide all the motivation I need. Rob is 15, Kerry is 13 and Kevin is 10. They are all involved in sports and other after-school

activities that require a lot of scheduling and running around. Some days, I might be struggling with fatigue or just feeling down, but if they need a ride somewhere, I get off the couch and do what needs to be done. Once I'm on my feet I am able to keep going.

I miss working, but I keep in touch with friends from the fire station, attending picnics and community events with them. I'm also able to spend more time volunteering at my daughter's school and helping out my parents, and that is gratifying. ■

“ Sometimes it's hard to accept the changes I've been through, but I'm still getting better and adjusting to the “new normal.” The main thing is that I'm here for my family and to see my kids grow up, and that gives me something to look forward to.”

—Robert, transplant recipient

### Your sense of the future

During treatment and early recovery, thoughts or fears about the future can be overwhelming. The focus of your life is just getting through each day. Even though you may live with uncertainty or fear of recurrence, regaining a sense of optimism about the future is essential to your quality of life. Ask:

- How do I learn to accept uncertainty?
- How do I integrate change into my life?
- How do I live for today and plan for tomorrow?
- What's next for me?

# Coping with grief



**W**hile there is much to celebrate along the road to recovery, many transplant recipients and their families may also experience grief for things they have lost. These may include lost opportunities, dreams for the future, changed relationships, financial difficulties or the loss of people you may have befriended during your treatment.

Dealing with grief is another stage in recovery. There is no single best way to work through grief. How you choose to deal with it will depend on your personal beliefs and motivations. The important thing is that you acknowledge it and work through it in a healthy, constructive way that works best for you. NOT dealing with grief can make it worse. The longer you ignore the

signs the longer it lasts and the more damaging it can be to your physical and emotional health.

## Recognizing the symptoms of grief

Becoming aware of grief is the first step toward healing.

- **Shock and numbness:** You may feel a flatness or detachment from the world. The feeling of numbness may be an emotional defense against experiencing fear and pain associated with loss.
- **Yearning and searching:** You may have trouble accepting the changes you've been through, leading to frustration and disappointment.
- **Disorganization and despair:** Grief can make it hard to concentrate, to make plans and follow through. This can lead to depression.

## Working through grief

You can work with family, friends, a faith community or professional grief counselors to identify the sources of your grief and help you develop coping strategies. These might include:

- Finding ways to experience and express your grief.
- Identifying emotional triggers like key dates, activities or associations and making plans to cope with them.
- Committing to take care of yourself by being healthy and active.
- Establishing new, or renewed relationships.
- Accepting your experience and rebuilding your life.

## Understanding survivor's guilt

When first diagnosed, many patients ask, "why me?" Many survivors ask themselves the same question. They grieve the loss of other patients who did not survive. Such loss can lead to difficult and complex emotions often described as "survivor's guilt." Survivor's guilt can prevent you from feeling truly happy, or may make you feel worse after enjoying something.

Survivor's guilt may also affect people around you, if they also feel guilty about experiencing joy or sharing their experience with you. Survivor's guilt can affect your physical and emotional health, relationships, your ability to work and move forward in your life.

Some survivors find it helpful to think in terms of honoring the memory of those they have lost by living as fully and joyfully as they can. But it's not always easy to do.

If you or your loved ones think you need help dealing with grief or survivor's guilt, talk to your medical team to find out what resources are available to you. ■

## ► Changes in spirituality and faith

# Spirituality

## Finding “meaning”

**M**any survivors describe their experience as giving their lives new meaning. Others struggle to find a meaning, or purpose, for what they’ve been through. Still others reject the idea that there is any meaning and prefer to move on, “playing the hand they are dealt.”

Everyone coping with life-threatening illness and recovery has their own beliefs and perspectives about religion, spirituality and faith. When patients, caregivers, family and friends have different opinions, it can cause conflict.

- Individuals with a strong faith tradition can feel hurt or frustrated when others do not share their particular faith or value it in the same way.
- People who are not religious can be offended by people who urge them to embrace their beliefs.
- People whose faith is changing can be upset by people who are critical of the changes.

Some survivors describe their experience as a blessing. Others would not.

Whether you have found new meaning, become stronger in your faith, or changed or given up your ideas completely, how you interpret your experience is a personal part of your journey. You have the right to your own beliefs and practices.

Find support that is right for you, and don’t be afraid to respectfully assert yourself if your beliefs are challenged in a way that is not helpful for you.

Respecting differences in our beliefs can help survivors and their loved ones support each other in a way that is truly helpful.

If you are interested in exploring your

spirituality as it relates to illness and recovery, it can be helpful to talk to others with similar questions, beliefs and experiences. Keeping a journal, reading books on the subject, talking to clergy, attending gatherings and engaging in religious practices can also be helpful.

Contact your hospital or health care team to find local faith-based organizations that offer support for survivors. ■

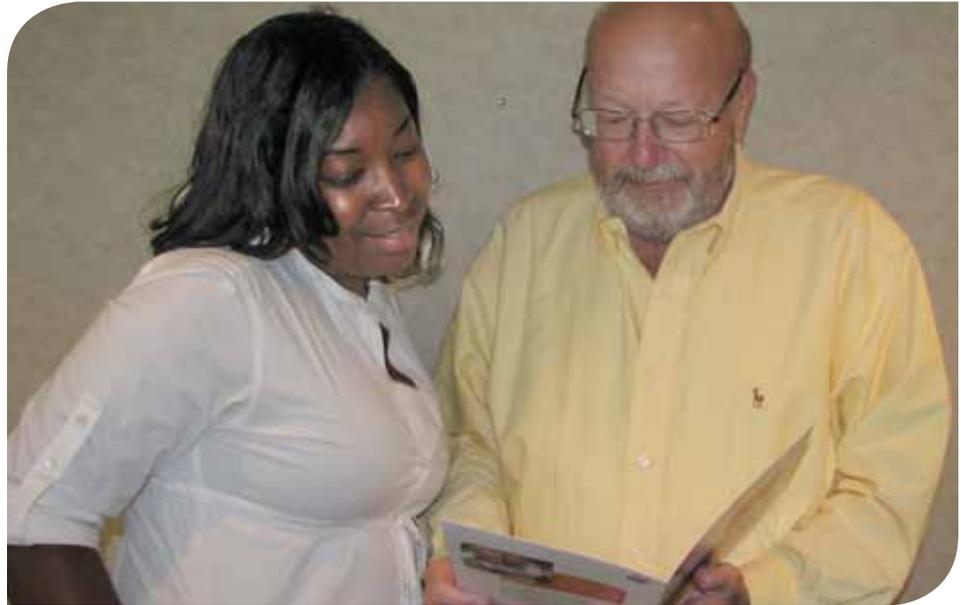


Everett, transplant recipient, with his family

# Giving back after transplant

**M**any transplant recipients feel a strong desire to help others as a way of showing their appreciation for all the support they received. Sharing your knowledge and insights to help others is a great way to put your experience to good use. If this appeals to you, consider the following opportunities:

- **Participate in a support group.** Even if you feel that you don't need a support group any more, you could use your experience to help newcomers.
- **Mentor patients.** Make yourself available to talk to other transplant patients, sharing your experience and encouragement as someone who understands what they are going through (BMT InfoNet and nbmt-LINK offer peer support programs).
- **Share your story.** Whether one-on-one, through the media, online or through a publication, your story can make a difference to others. As a survivor, you are in a unique position to provide motivation, hope and advice. If you would like to share your story with us, please e-mail us at [mystory@nmdp.org](mailto:mystory@nmdp.org).
- **Raise awareness of transplantation and the need for donors.** Contact a local donor center to learn how you can support Be The Match® donor recruitment efforts. Visit [BeTheMatch.org](http://BeTheMatch.org) to learn how you can get involved.
- **Support the Be The Match Foundation®.** The foundation uses contributions to add more people to the Be The Match Registry, help patients with financial needs and fund transplant research. Visit [BeTheMatch.org](http://BeTheMatch.org).



Volunteers, Tenille and Steve, serve on the Patient Advisory Board.

## Do only as much as is right for you

Sharing your transplant story to encourage and motivate others can be tremendously rewarding, but it's important to recognize your limits. Survivors who find themselves in high demand as speakers, honored guests and frequent volunteers, might feel guilty about turning down requests. It can help to keep your priorities in mind and maintain good boundaries. Accept only the invitations that appeal to you and let others pass. Making choices that are right for you is important to your quality of life.

## Know when to say “when”

Some survivors become passionate about raising awareness, recruiting donors and supporting their favorite organizations. Their efforts help save lives, and some see this role as their new life's work.

Others prefer to leave their experience behind. They'd rather stop being seen as “a survivor,” and simply live – like everyone else.

This can be especially true for younger patients. Children and their parents may be in high demand to share their stories because they are so inspiring. Parents may be eager to give back and young survivors may thrive on the attention. But as they get older, they might change their mind. It's okay to make that transition from surviving to living – to think of yourself as having “graduated” from that stage of your life. Your experience will always be an important part of your personal history, but it doesn't have to define you.

However you choose to think about your illness and recovery – if you want to use the experience to motivate others, or if you'd rather leave it behind and move in a new direction – the choice is yours. ■

# Post-transplant support & resources

One of the most important things to remember throughout the recovery process is that you are not alone. **Be The Match**<sup>®</sup> is dedicated to supporting patients, caregivers and families. We offer you confidential one-on-one support, financial guidance and free educational resources. We're here for you.

**Call:** 1 (888) 999-6743 **Learn:** [BeTheMatch.org/patient](http://BeTheMatch.org/patient)

**Order:** [BeTheMatch.org/request](http://BeTheMatch.org/request) **Email:** [patientinfo@nmdp.org](mailto:patientinfo@nmdp.org)

In addition to the national organizations below, you can also explore local community resources or online communities. Ask if your transplant center offers a buddy program that can connect you with other transplant recipients or caregivers interested in sharing their experiences and seeking solutions.

## American Cancer Society

As a cancer survivor you have special needs and interests. Learn to develop healthy habits now that your treatment is over. Connect with other survivors and find opportunities to volunteer.

**Website:** [cancer.org](http://cancer.org)

## Blood & Marrow Transplant Information Network (BMT InfoNet)

Caring Connections is a network of more than 800 transplant survivors who provide emotional support to patients and caregivers through phone conversations, e-mails, texts, letters or visits. If you or someone you love has undergone a bone marrow, blood stem cell or cord blood transplant and would like to join the Caring Connections network of volunteers, please visit: [bmtinfonet.org/services/support/volunteer](http://bmtinfonet.org/services/support/volunteer)

## BMT Support Online, Inc.

Offers online peer-support groups for transplant patients, survivors and caregivers.

**Website:** [bmtsupport.org](http://bmtsupport.org)

## National Bone Marrow Transplant Link (nbmtLINK)

"Peer Support on Call" provides emotional support through one-on-one conversations with trained peer support volunteers who are bone marrow/stem cell transplant survivors, caregivers and marrow donors. If you are interested in becoming a Peer Support Volunteer, please call nbmtLINK at **800-LINK-BMT** (800-546-5268).

## National Cancer Institute (NCI)

NCI is dedicated to enhancing the length and quality of life of cancer survivors.

**Website:** [nci.gov](http://nci.gov)

## Find more resources with ExploreBMT™

To find trusted resources from other organizations that can help you in your situation, visit [ExploreBMT.org](http://ExploreBMT.org). ExploreBMT is a one-stop resource for patients, families and caregivers impacted by a disease treatable by a blood and marrow transplant. This easy-to-search online tool provides direct access to information about blood and marrow transplantation from many patient-focused organizations.

## Conclusion

This issue of *Living Now* is the sixth and final issue in the series. You can find the previous five issues and a special issue for caregivers at [bethematch.org/request](http://bethematch.org/request). Looking for ways to stay connected? Subscribe to *Living Now* e-newsletter to engage with other transplant recipients and share your story (see side panel).

We hope you have found these newsletters helpful and invite your feedback so we can continue to improve them. Contact us at [patientinfo@nmdp.org](mailto:patientinfo@nmdp.org) or call 1 (888) 999-6743.

## Living Now e-newsletter:

Staying connected after transplant just got easier



This free e-newsletter is designed just for transplant recipients and their families.

- **Hear stories** and experiences from others.
- Be the first to know about **new resources** and research.
- Get **tips and ideas** for healthy living after transplant.
- **Share** your experiences.

**SUBSCRIBE NOW**

[BeTheMatch.org/patient-ews](http://BeTheMatch.org/patient-ews)

# Living **now**

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**Issue 6: 2 years & beyond**

## Recovering a sense of purpose

### Invitation to submit stories

Do you have tips or information about your post-transplant experience that you would like to share with other patients? If so, please contact us at: [mystory@nmdp.org](mailto:mystory@nmdp.org) or 1 (888) 999-6743.



# Living **now**

**Issue 6: 2 years & beyond**

### Inside this issue:

## Recovering a sense of purpose

### Reclaiming your:

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**Rob, transplant recipient, and his wife Teresa**