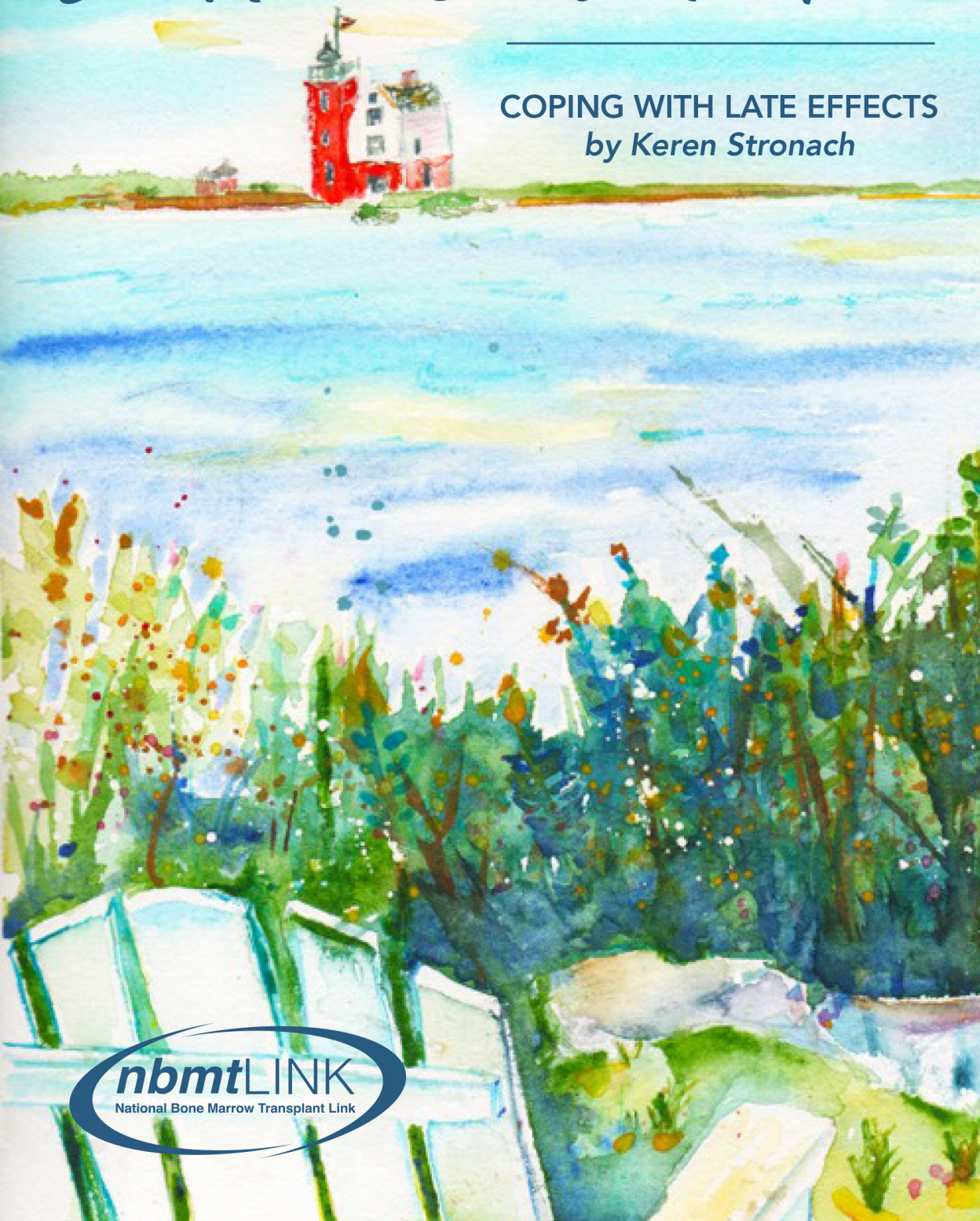
Survivorship:
Bone Marrow / Stem Cell Transplant



COPING WITH LATE EFFECTS

by Keren Stronach

nbmtLINK
National Bone Marrow Transplant Link

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I would like to thank the survivors and caregivers who responded to our survey and shared their personal stories; Myra Jacobs for having faith in me and encouraging me to write; Melinda Clynes and staff at the National Bone Marrow Transplant Link for continuing to support countless cancer survivors; and to friends and family, and, yes, even strangers who, through their daily actions lift up others and make this world a better place.
- Keren Stronach, 2020

Founded in 1992, the National Bone Marrow Transplant Link is an independent, nonprofit organization funded entirely through the generosity of individuals, corporations and foundations. Tax-deductible contributions are welcomed and enable us to create and sustain programs and services.

The mission of the nbmtLINK is to help patients, caregivers, and families cope with the social and emotional challenges of bone marrow/stem cell transplant from diagnosis through survivorship by providing vital information and personalized support services.

The information in this guide should not be a substitute for medical advice, and the listed resources are not intended to be endorsements. Please consult with your physician regarding your medical decisions and treatment.

For additional copies of this booklet, please contact National Bone Marrow Transplant Link
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Books may be ordered from the website at www.nbmtlink.org.

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The National Bone Marrow Transplant Link (nbmtLINK) is very grateful to author Keren Stronach, who originally authored this book and has since agreed to revising it, and who, like many other survivors, realizes the importance of finding a "new normal" while continuing to cope with the late effects of transplant.

We would also like to acknowledge the transplant patients, survivors, and caregivers who generously shared their experiences and practical recommendations. The courage of these individuals inspires us every day!

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The National Bone Marrow Transplant Link, established in 1992, strives to help patients, caregivers and families cope with the psychosocial challenges of bone marrow/stem cell transplants from diagnosis through survivorship. We provide vital information through valuable resource books such as this one. Many of the resources listed below are available online. Additionally, specialized and personalized support services are available through our licensed staff social worker.

We offer patients, families and health care professionals these resources and more:

- Lunch & Learn Monthly Free Call-In Programs
- Award-Winning Publications
- Marrow Masters Podcast Series
- Informative Annual Webinars
- Peer Support Mentoring Program (Be A Peer or Request A Peer)
- Information and Referrals through our Licensed Staff Social Worker
- Celebrate Second Birthday Program
- Select Publications Now Available as Audio Books
- Healing Arts Programs

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PROLOGUE

I would like to imagine that over the years, I have become more expert at navigating uncertainty, at facing my mortality, at living a life that is so different from what I imagined. And for now, I feel lucky and blessed to be where I am – relatively healthy and alive. But I know that all this can change in an instant – a recurrence or another malignancy, a freak accident, or a broken limb. The following parable anchors me and gives me the courage to move on and face the future.

As many of you know, Itzhak Perlman is a famous violinist who contracted polio as a young boy. As a result, he walks with great difficulty and with the aid of crutches. One day, Perlman was scheduled to give a recital at Carnegie Hall. As usual, he came on to the stage with crutches, laboriously walking to his seat. A few bars into the symphony, one of his violin strings broke with a loud popping sound.

The conductor stopped the orchestra, and the audience held its collective breath as it waited to see what would happen next. Would someone appear from backstage with a new violin? Would Perlman pull a new violin string out of his pocket? Instead, after a short pause, he nodded to the conductor to resume where he had left off.

Everyone knows that a violin cannot be played with three strings. That evening, Perlman refused to know this. He played the entire symphony on three strings. When the symphony ended, the audience rose with thunderous applause, clapping and stomping and shouting. When the audience finally quieted down, he said:

> *"It is the artist's task to find out how much music you can make with the instrument that you have."*

Survivorship is about living life fully with changed instruments: changed bodies, changed psyches, and changed perceptions. We all emerge from our transplant different than we were. Many of us may be changed physically or have an altered perception of our vulnerability and sense of mortality. The challenge is to figure out how to live as loudly, fully, and richly as we can, given who we are today, post diagnosis and post transplant. We may not be able to do as much or soar as high as we used to, but survivorship is about finding ways to live full, rich, and meaningful lives as we are today.

INTRODUCTION

Before my first bone marrow transplant in 1994, I believed that my life would return to what I knew to be normal after the transplant. The information I was given about what to expect post transplant was minimal. Most doctors mentioned the possibility of long-term health problems resulting from the transplant, but they also told the stories of a few star patients who went back to their lives at full steam, returning to competitive tennis or running, just as strong as before. In my mind, I latched onto these positive stories, imagining myself a few years down the road, vigorous and healthy again.

However, two BMTs later, my body, skin, strength, stamina and approach to life (and death) have profoundly changed. The new normal is both better and worse than I expected. My physical health and energy level are nothing like what they used to be. It is almost as if I am in a new body, which I have had to get to know and identify with. Whereas before the transplant, I prided myself on being very athletic, healthy, and energetic, I am no longer these things. I deal with ongoing chronic Graft Versus Host Disease (GVHD) and take medications on a daily basis. And my energy, while allowing me to function normally, is a fraction of what it used to be.

I certainly cannot travel to all the places I once hoped to visit or have the career I once imagined for myself. Emotionally, the story is more complex. Overall, I am content and happy, possibly more so than before the transplant. I appreciate life more; I am more accepting of my shortcomings; I treat myself more kindly; and I am more focused on enjoying this short life. I also still grieve the early loss of my health, vigor, fertility, appearance, and the imagined trajectory of my life had it not been for the aftereffects of the transplant.

Navigating the bumpy post-transplant journey is not easy, particularly if we experience transplant aftereffects. Very few, if any, of our friends experience our symptoms. And often, the physicians caring for us outside of the transplant center are not savvy about the late effects of transplant.

This guide provides information and resources to help you on your journey in the years and decades following your transplant. Much of the information in this guide was obtained from surveys that were filled out by long-term survivors, a few caregivers, peer-reviewed scientific journal articles, lectures by experts in the field, and discussions with survivors and medical personnel. The kaleidoscope of stories of shared struggles, losses and resilience speaks to the incredible capacity of individuals to weave together meaningful and rich lives despite adversity, and, in many cases, ongoing health problems.

Keep in mind that the information, recommendations, survivor quotes, and products/medications mentioned in this booklet are not endorsements nor intended as medical advice. Always consult with your physician about your medical decisions and treatment.

Please note that some of the survivor quotes have been modified or condensed for grammatical and space purposes.

For readers who would like to learn about the basics of the transplant process, the nbmtLINK's booklet, *Guide to Bone Marrow/Stem Cell Transplant: What to Expect and How to Move Forward* is available from the National Bone Marrow Transplant Link. Please visit www.nbmtlink.org or call 800-LINK-BMT to find out how you can receive a copy of this publication. You'll find other information at www.BMTinfonet.org. Also, www.nmdp.org has additional resources.

CHAPTER 1
LONG-TERM SURVIVORSHIP

This guide is about long-term survivorship. It is about the years following the intensity of a transplant and the "new normal" that emerges.

For the purpose of this guide, we are defining a long-term survivor as anyone who is two or more years after a bone marrow, peripheral blood stem cell or umbilical cord blood transplant. Hematopoietic cell transplant (HCT) is the medical term encompassing all of these terms. In this book, we refer to these types of transplants using the terms "transplant" or "BMT."

More than 60,000 such transplants are performed worldwide each year, according to the American Society for Transplantation and Cellular Therapy (*Biology of Blood and Marrow Transplantation* monthly journal, 2015). As treatment statistics improve and more individuals are added to the community of long-term survivors, the number of people experiencing chronic health conditions from the aftereffects of their disease and its treatment will grow as well.

It is therefore increasingly important to provide a realistic picture of the post-transplant experience in all its complexity and diversity.

The goal of this guide is to shed light on the challenges that individuals face after a transplant, and to provide useful information and resources on how to cope with these challenges.

Although many of us may continue to experience some chronic health problems as a result of the transplant, it is important to remember that we can continue to live good lives despite post transplant challenges. With persistence and good follow-up treatment, many of the aftereffects can be reduced.

Long-term Effects of the Transplant

The transplant experience can affect us physically, emotionally, mentally, and spiritually—with some people facing more effects than others. It can also affect our social relationships and our ability to work in the same profession or with the same intensity as in the past, and all this impacts our quality of life.

Some survivors, once they are two or more years out, leave the transplant experience behind with few or no lingering problems. Others, however, may deal with ongoing challenges and complications that can affect many aspects of life.

Quality of life of patients who undergo transplantation is negatively affected in the period

right before and after their transplant.[1] It is not surprising that quality of life worsens as the severity of symptoms worsens.[1, 2]

However, one year after transplant a majority of people report that their overall quality of life is as good as before their transplant. Still there are specific areas where people have more difficulty, including in sleep, sexual function, fatigue and return to being as physically active as before their diagnosis.[3]

Survivors do report having a higher risk of other medical problems compared to the general population or other cancer survivors. These include infections, second cancers, bone loss, and cardiovascular, pulmonary, renal and endocrine dysfunction.[4] Survivors can suffer from significant late effects that include diseases of the cardiovascular, pulmonary, and endocrine systems; dysfunction of the thyroid gland, gonads, liver and kidneys; infertility; iron overload; and bone diseases.[5]

Although some survivors view their health as worse than a typical person their age, they also might notice positive changes, such as...

- greater personal growth,
- enhanced appreciation for life,
- greater appreciation of friends and family,
- different priorities, and
- a shift in life expectations.

How these gains and losses play out is different for each individual, with some people experiencing more of the benefits and others feeling the losses more acutely.

> "I feel that I lead a more balanced life now. I definitely take more time to appreciate what life has to offer. However, I am constantly fearful of what health problems lie ahead (relapse, secondary cancers, etc.)."

> "Since the transplant I have experienced physical problems as well as depression, fear, and profound anxiety that have been very debilitating."

> "Life after transplant is tough. I realize the transplant is always going to be part of my life. I have a scar where my Hickman catheter used to be; I have a bump on my scalp where a port was in my head. I wonder why I got sick since I had led such a healthy lifestyle before. I never even took aspirin before I got sick. My world has changed so much."

> "I feel mostly as strong and healthy today as before the transplant. The difference is that I can't push myself as hard. I need to take breaks when I start to falter (rather than work through it)."

> "I feel better and healthier since the transplant. I am back 100%."

Quality of Life Post Transplant

Quality of life is complex and is tied to many factors, including emotional support, personal belief system, financial resources, access to good medical care and other resources, as well as individual coping abilities. Chronic diseases such as cancer have a strong influence on both quality of life and physical health. Together these comprise the concept of health-related quality of life: the complete state of physical, social, and psychological functioning.[6]

Assessing the change in quality of life before and after the transplant is complicated by the fact that shifts in expectations and priorities may change how survivors evaluate their quality of life. Also, deterioration in health or sexual functioning may be counterbalanced by strengthened social bonds or enhanced spirituality, all of which go into the general mix that makes up what we call quality of life.

Overall, survivors do more poorly on many measures of quality of life when compared to individuals who have not undergone a transplant.[1,2] Despite this, however, 60% of survivors are satisfied with their lives and report good to excellent quality of life in the initial years post-transplant.[7]

Survivors' attitudes and coping strategies impact their behavioral and emotional reactions, which, in turn, affect overall quality of life and physical functioning.[6] In short, adjusting your attitude and finding healthy ways to cope with the new normal are part of improving your health-related quality of life and overall quality of life.

> "Before the transplant I took my good health and so much else for granted. Now, I deal with many small lingering health issues, but I use a different measuring stick to evaluate my life. What I once would have considered only acceptable, I now consider good, and I appreciate both the big and the little things more."
>
> "The transplant experience helped me grow as a person. I learned things about myself and fellow humans that I would not have considered prior to being sick. I think I am a better, happier person as a result of the experience."
>
> "Overall, I feel a bit depressed more often than before. I become anxious easily now in the face of unexpected changes in plans."
>
> "I am weaker in mind, body, and spirit. I continue to try to strengthen all and accept that both age and illness take their tolls."
>
> "I'm actually a happier and more well-balanced person than I was before the transplant. I treat myself better and try not to take things too seriously. I don't always succeed, but I do recognize when I'm blowing things out of proportion."

Adjusting to the New Normal

Figuring out how to incorporate the physical, emotional, and spiritual changes of the transplant into our lives is complicated and takes time. Often, our sense of who we are is challenged. We may need to discard some of the old notions that we had about ourselves, adjust some of our goals, and make some modifications to how we live.

For some people, experiencing the new reality post transplant is extremely stressful. There is no easy template to deal with fear of recurrence, chronic health conditions, changed stamina, and changed perceptions of self.

However, over time, a large majority of survivors do incorporate the changes of the transplant into their lives, and a new normal emerges.

> "One of the greatest challenges for me after the transplant was learning to identify with and like my new self—the one who is not very athletic, who gets sick easily, who has bags under her eyes. For a long time, I kept wanting to apologize for this new self because, in some sense, I didn't see it as the real me. Now I can look at this new self with more acceptance, but liking the new me is still a work in progress."

> "I can no longer wind surf, kayak, mountain climb, mountain bike, downhill or cross-country ski, or jog. I can walk, snorkel, swim, hike, garden and bird watch."

> "The transplant tremendously impacted my perspective. I used to think I was invincible. The transplant was humbling."

> "The new normal is not a bad normal, just different. Perspective is everything. Life goes on. This is how I am now."

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