

Dan Poynter's

Transplant Handbook for Patients

Replacing Stem Cells in Your Bone Marrow

Transplant Handbook for Patients

Replacing Stem Cells in Your Bone Marrow

Dan Poynter

 **Para Publishing, Santa Barbara, California.**

Transplant Handbook for Patients

By Dan Poynter

Published by:

Para Publishing

Post Office Box 8206

Santa Barbara, CA 93118-8206, U.S.A.

info@ParaPublishing.com, <http://ParaPublishing.com>

Copyright © 2014 by Dan Poynter

Printed in the United States of America

All rights reserved. No part of this book may be reproduced or transmitted in any form or by any means, electronic or mechanical, including photocopying, recording or by any information storage and retrieval system without written permission from the author except for the inclusion of brief quotations in a review.

Some images copyright by <http://www.ClipArt.com>

ISBN ebook edition: 978-1-56860-163-2

ISBN softcover edition: 978-1-56860-164-9

<http://TransplantHandbook.com>

Library of Congress Cataloging-in-Publication Data

Poynter, Dan.

Transplant Handbook for Patients: Replacing Stem Cells in your Bone Marrow

/ Poynter, Dan.

p. cm.

Includes bibliographical references and index.

ISBN 978-1-56860-163-2, 1-56860-164-9

1. Health & Fitness.

2. Diseases/Cancer/Stem Cell-Bone Marrow Transplants. I. Title.

Contents

- Chapter 1** Medical problems that new stem cells might help.
- Chapter 2** You Have Choices!
- Chapter 3** Stem Cell Donors
- Chapter 4** Testing: You and Your Donor
- Chapter 5** What Your Donor can Expect
- Chapter 6** Preparing to Leave Home for Two Months
- Chapter 7** Port Installation and Maintenance
- Chapter 8** Your Hospital Stay: Transplant Procedure
- Chapter 9** Hospital Events, Day-by-Day.
- Chapter 10** Post-Transplant Care
- Chapter 11** Returning Home
- Chapter 12** Caregiver's Role
- Chapter 13** Paperwork
- Chapter 14** Expenses and Insurance
- Afterword.**
- Appendix**
Resources, More Information: Books, Pamphlets, Websites,
Clinical Trial Locators, Webcasts, & Support Groups.

About the Author

Dan Poynter is the author of more than 130 books, has been a publisher since 1969, and is a Certified Speaking Professional (CSP).

He is an evangelist for books, an ombudsman for authors, an advocate for publishers, and the godfather to thousands of successfully published books.



His seminars have been featured on CNN, his books have been pictured in *The Wall Street Journal*, and his story has been told in *The New York Times*. The media come to Dan because he is the leading authority on book publishing.

Dan travels more than 6,000 miles each week to share, inspire, and empower writers, publishers, and professional speakers through keynotes and seminars.

See his Para Publishing website at <http://ParaPublishing.com> and his Wikipedia bio: http://en.wikipedia.org/wiki/Dan_Poynter



Dan is a pilot and has been a skydiver since 1962. He has held every position in the parachute sport and industry and is a trustee and curator for the National Skydiving Museum. See http://www.slideshare.net/Dan_Poynter/dan-poynterparachutes-skydiving-aviation

Dan runs his publishing company, Para Publishing, in Santa Barbara.

Acknowledgment

I am deeply indebted to many wonderful people: Gary Schiller, MD; Daniel Greenwald, MD; Tidi Lambert, RN; Lee Schlichtemeier, MD; Sara Gerhards, MD; Karolina Faysman, Nurse Practitioner; José Fabian, Clinical Social Worker; Peter Ji, General Manager of Tiverton House; Carol Wolf, RN; Daniel Kyburz, fellow patient with Leukemia; C. Richard Ma, transplant patient; Bill Gerrow, cancer patient; DA Metrov, cancer patient; author/publisher Gordon Burgett. Some of them peer reviewed all or part of this book.

Thanks to Elizabeth Beeton of B10 Mediaworx for copyediting, ebook conversion, and posting.

I am also indebted to Youtube.com for making so many valuable videos available and to Wikipedia.com for definitions and explanations. They are referenced in this book.

I am deeply indebted to my caregiver and girlfriend Maryjean Ballner for standing by me and for her content-edit of this book. She observed what was happening to me during this adventure.

Thanks to my donor-sister

Like you, special thanks have to go to our donors. Mostly, I must thank my sister Margaret Goldsmith, PhD. She is my donor, advocate, fabulous listener, and greatest supporter.

For one who is not accustomed to easily accepting gifts, the gift of Maggie's stem cells was overwhelming. I became aware with a new consciousness—I was given a new lease on my life.

Maggie's stem cell donation was a palpable demonstration of love, and feeling. "Lucky" barely scratches the surface of the emotions of gratitude coursing through my body. Yes, Maggie's donation was a gift that will keep on giving.

I sincerely thank all these fine people, and I know they are proud of their contributions to the medical community as well as to this Work.

Introduction

Dan spent months researching and writing the *Transplant Handbook for Patients*. He read all the books on the subject and everything he could find online.

But then he went through the transplant procedure as a patient and rewrote everything according to what he learned. Therefore, this book reflects what only a patient could know.

No Index

The ebook edition of this book does not have an index because the page numbering will vary depending on the ebook reader used. Use the search feature in the ebook to locate every occurrence of the key word.

Ebook versus paper

This is an "enhanced" book. It references many website addresses for more information. The URLs in the paper edition can be typed in but the work is tedious and it must be exact. In the ebook, you simply have to click on the URL.

The definitions and other written material are very helpful but the videos let you see the procedures in action. Be sure to watch the videos.

Copy>Paste all PDF URLs in this text. Some web browsers will not be able to open them.

Being positive and working at recovery is a major element in getting well sooner.

**Your attitude,
not your aptitude,
will determine your altitude.
—Zig Ziglar, motivational speaker.**

Disclaimer

THIS IS NOT A MEDICAL TEXT. It is a practical handbook for the patient. It tells what may happen if you elect to pursue a stem cell transplant. This book provides encouragement and support in the face of a life-threatening condition. Stem cell transplants are not always successful. Do not do any of the things suggested in this book without clearing them with a member of your transplant team.

Even great books have their limitations. This book is designed to provide information about the subject matter covered. It is sold with the understanding that the publisher and author are not engaged in rendering medical, legal, accounting, or other professional services. If expert assistance is required, the services of a competent professional should be sought.

It is not the purpose of this book to reprint all the information that is available elsewhere, but to complement, amplify, and supplement other texts. For more information, see your bookstore.

Every effort has been made to make this book as complete and as accurate as possible. However, there may be mistakes both typographical and in content. Therefore, this text should be used only as a general guide and not as the ultimate source of transplant information. Furthermore, this book contains information that is current only up to the printing date.

The purpose of this manual is to educate and entertain. The author and Para Publishing shall have neither liability nor responsibility to any person or entity with respect to any loss or damage caused or alleged to be caused directly or indirectly by the information contained in this book.

If you do not wish to be bound by the above, you may return this book to the publisher for a full refund.

For those who love to find mistakes, please send your corrections to the author for the next edition.

Chapter 1

Medical problems that new stem cells might help.

Nearly everyone has one of these diseases or knows someone who does. Here are some health challenges that may be helped. Medical progress is being made daily.

Alzheimer's Disease
Autism
Cancers
Cerebral Palsy
Diabetes
Epstein-Barr
Heart Disease
Hodgkin Lymphoma
Huntington's Disease
Immune Deficiency Diseases
Inherited Metabolic Disorders
Leukemia
Lou Gehrig's Disease, ALS.
Lung Disease
Lupus
MS
Multiple Myeloma
Muscular Dystrophy
Myelodysplastic Syndromes (MDS)
Non-Hodgkin Lymphoma
Parkinson's Disease
Severe Aplastic Anemia and Other Marrow Failure Syndromes
Sickle Cell Disease and Thalassemia
Spinal cord injury
And more.

To get the very-latest information, make a Google search for Stem cell + (the disease).

See an expanded list of diseases at <http://www.stemcyte.com/why-save-cord-blood/diseases-treated-with-stem-cells>

Also

<https://bethematchclinical.org/transplant-indications-and-outcomes/disease-specific-indications-and-outcomes/>

Using adult stem cells drawn from bone marrow and umbilical cord blood system cells, scientists have discovered new treatments for scores of diseases and conditions such as Parkinson's disease, juvenile diabetes, and spinal cord injuries.
--Nathan Deal

As many as 1 in 217 individuals may need a stem cell transplant during their lifetime.

A stem cell transplant is the replacement of damaged cells in your bone marrow with the infusion of healthy stem cells via your blood stream. Diseased or destroyed stem cells can be replaced.

A stem cell is a cell that can renew itself and send new cells out into the circulating blood. Stem cells are replaced through infusions; there is no surgery.

See the following transplant explanations:

Hematopoietic stem cell transplantation

http://en.wikipedia.org/wiki/Hematopoietic_stem_cell_transplantation#Donor_registration_and_recruitment

Bone Marrow/Stem Cell Transplantation

<http://www.cancer.gov/cancertopics/factsheet/Therapy/bone-marrow-transplant>

What to Expect

<http://www.nhlbi.nih.gov/health/health-topics/topics/bmsct/during.html>

Bone Marrow/Stem Cell Transplantation

<https://www.youtube.com/watch?v=49YputwJ6YM>
(YouTube video)

And for those already diagnosed with cancer:

Peripheral Blood Stem Cell Transplant

<https://www.youtube.com/watch?v=mQNG00H6X5g>

(YouTube video)

Stem cell transplant treatment is similar to cancer procedure: chemotherapy &/or radiation therapy is used.

The severity of a transplant is comparable to a heart transplant. In each case the survival rate is less than 100%.

Transplantation is a routine treatment that cures more than 90% of patients with blood disorders; when performed in the early stage of the disease if an optimal donor-recipient combination is available. Today, more than 330,000 transplants are carried out annually worldwide in 1327 centers in 71 countries and the numbers are increasing each year. Stem cell transplantation also remains the last hope for patients with advanced or stubborn blood disease.

There is little detailed information available on what patients can expect in a transplant procedure. Most books are geared toward the medical providers, not the patient. Those written for the patient usually follow one person's experiences and rarely provide clarifying detail. This book, on the other hand, is written from the patient's perspective. It will also be useful to medical providers to help them understand our experiences, feelings, and concerns.

In addition to this book, it is strongly recommended that you read some of the books listed in the Appendix and spend time researching online.

This book is not a substitute for instructions from your doctor, your transplant team, or other healthcare providers. As patients, each of us is unique in physical condition, health, age, family support, geographic location, etc. This is an account of my study and experiences. While your situation will be slightly different, the similarities will be remarkable.

The greatest frustration will be the unpredictability of your schedule. Much will depend on your progress in the hospital but even before that, you will be dealing with many appointments, people, schedules, medications, and procedures. Depending on your progress, many days will be unpredictable.

In the medical center, you'll also do a lot of waiting. Accept the inconvenience and make use of the time. Prepare by taking reading material, recorded music, and/or your tablet

Two years ago, I was diagnosed with MDS (Myelodysplastic Syndrome), Chromosome 19 trisomy. A blood analysis showed that my red blood cells were slightly low and my platelets were very low. A biopsy confirmed that I had an extra chromosome 19 (trisomy). The third chromosome was interfering with the production of blood cells.

We have 22 chromosomes plus X and Y that determine sex. We have two of each chromosome: one from our mother and one from our father. If there are three of any one chromosome (trisomy), there is a problem.

I discovered that 19 Trisomy is a very rare chromosomal disorder where there is an extra copy of chromosome 19 in some of my body's cells. It had not progressed into leukemia; I did not have cancer—yet.

Myelodysplastic Syndrome (MDS)

MDS is a bone marrow failure disorder. It is a collection of related diseases (syndrome) of the bone marrow where a common feature is low blood counts, and one of the blood cell types is not working properly (dysplasia). MDS can progress into acute myelogenous leukemia (AML).

Leukemia, by the way, comes from the Greek and means “white blood.” When a person has leukemia, the bone marrow produces a huge number of abnormal, immature white cells. These cells do not attack bacteria and viruses as they are designed to do; they simply take up space, crowding out production of the normal, working bone marrow cells.

For information on MDS, see the Wikipedia entry for [myelodysplastic syndrome](#).

Chromosome 19 Trisomy is the same bone marrow disorder experienced by Robin Roberts, ABC newscaster of *Good Morning America*. She underwent a transplant in late 2012 and, as of this writing, is back at work full-time and appears to be cured.

See [“Robin Roberts on Her Cancer Battle.”](#)



To increase my platelets and white blood cells, I was treated with five daily shots of Neupogen. The shots had little effect. A subsequent platelet transfusion did not increase the platelets very much or for long. Next, I was treated with five weekly chemotherapy rounds, spaced a month apart, of Vidaza (generic: Azacitidine). The results were unchanged.

A Little More About Me

I mention my situation to help you to understand what I went through, why I made certain decisions, and felt that some things were important. Some of my parameters will fit you and others will not. For example, I live in Santa Barbara, 100 miles up the coast from the UCLA Medical Center. My situation is different from someone who lives in Los Angeles.

I am:

—Independent. I've spent most of my life living alone as opposed to being surrounded by family.

—Introverted. I am happier alone than in a crowd situation.

This is an advantage for an author.

—Impatient. Why do two things at a time when you can do three?

I am 74 years old, do not take medications of any type, I've never smoked, and am not overweight. I do not drink coffee, do not drink soft drinks, drink only distilled water (no bacteria) but do like three or four beers in the evening.

Age use to be an issue. Transplants were rarely performed on people over 60. New studies have shown that other factors, such as physical condition, are much more important than age. At 74, I am further evidence that age should not be a barrier.

Herbal Supplements

I consume a number of vitamin/herbal supplements. They may be responsible for my complete blood count (CBC) being fairly constant over the past two years.

A few years ago I was diagnosed with high cholesterol. Now I take lecithin pills daily and have lowered my cholesterol count from 212 to 135.

My blood pressure average is 145/82. I consume some supplements to lower these numbers and stopped drinking

coffee months ago. Neither the supplements nor lack of coffee have lowered my blood pressure readings.

Years ago, my cat Cricket developed a knee problem. It was obviously very painful. The veterinarian checked him out and said the knee joint was wearing on one side and building up on the other, causing pain. I asked my friend and celebrity nutritionist Patricia Bragg for advice. Her reply was: "Cod liver oil." Why? "It oils the joints." Each day, I would squirt one A&D capsule onto his food. He loved it. And he lived another year and a half, to the age of 21 years.

Ever since, I have consumed one A&D capsule daily. It overcomes minor back and joint pain.

—Dan Poynter

The above affects my experiences and advice. Your experiences will have some similarities and some differences.

Who Needs to Know?

Some people do not want anyone to know about their transplant while others broadcast their medical journey everywhere. Some even blog daily as they venture through their transplant experience.

CaringBridge provides a free, private, personalized website for easy communication with family and friends during a serious medical condition. As a patient, you may post your daily progress.

During 2013, CaringBridge hosted 73,956 subsites, posted 4,712,997 Guestbook messages and had more than 43-million site visitors.

Family and acquaintances can post supportive messages on the site at CaringBridge.org.

UCLA hosts CarePages.com

**Three may keep a secret
if two of them are dead.**

—Benjamin Franklin

Months may pass between your diagnosis and transplant. If you mention your diagnosis early, could you miss out on a job promotion or be shunned by some of your colleagues?

Interestingly, most patients keep the medical challenge a secret. They do not tell anyone outside of medical personnel and their immediate family.

Years ago, a friend of mine broke a leg skydiving. The doctor offered him a pair of Canadian Crutches, also known as "forearm crutches." He rejected the offer and requested standard wooden, underarm crutches. The doctor inquired why.

He replied that underarm crutches made him appear to have been in a sporting accident while forearm crutches would make him look like a disabled person. He was afraid people at work and on the New York subway would shun him.

He knew that with the wooden crutches people would approach him and ask "skiing"? And then he could proudly brag: "No, I broke my leg skydiving."

I am an author, publisher, and professional speaker. I offer written, spoken, and consulting services to the publishing industry. If clients were to find out about my medical challenge, it would be devastating to my business. Much of my income would dry up.

I chose to restrict my revelation to medical people. This included my dermatologist and dentist before they performed any work on me. Months later, I revealed the situation to my siblings when I was searching for a donor. It was much, much later when I revealed the situation to my girlfriend and my office manager. I do not plan to spread the word any further until I am past any danger point and am several months into medical recovery.

Both authors and professional speakers take advantage of new experiences. We can be heard to say, "It was not pleasant but it provided me with a new story."

To me, the transplant procedure is an opportunity, an adventure. It has given me a new subject to research and write about. The opportunity has not produced any stress, anxiety, or depression; it has simply changed some priorities. Now I'm spending more time researching and writing the book.

Another bonus sprang from this transplant adventure. My three siblings and I are scattered across the US. We see each other only occasionally and then for short periods of time.

Now we email and telephone each other much more often. Because of this medical issue, we are discovering that we have similar characteristics. For example, we each have internal clocks. We can set our brains to wake us up at any particular time. We all have small or sensitive bladders. The four of us urinate quite often. None of us care to drive. By the way, I've flown more than three million miles on United Airlines.

My medical issue has brought the siblings closer together.

Transplant Team

Your transplant team will consist of doctors, nurses, nurse practitioners, coordinators, social workers, housekeepers, dietitians, priests/ministers, and more. Their jobs are to take care of you, guide you, and answer your questions.

If you are like me: insured, not on meds, nonsmoker, no allergies, and not overweight, these meetings will be short. The consultants who are coming to see you will seem disappointed and leave because they have nothing to offer you at that time. Before they meet you, all they see is your age, gender, and a diagnosis—and they make assumptions. When they see the person wearing clothes and shoes, they look for the "patient." When you state you are healthy, no allergies, not on meds, their role in your care coordination becomes moot.

Many patients like to write their questions in a notebook and then write in the answers. For the best understanding of what is going on, ask questions.

I Wrote This Book for You

I love to write books. Since 1969 I have written 132 books of nonfiction and one work of fiction. I write about what I do or what interests me at the time. See the [Dan Poynter Wikipedia entry](#).

I spent much of my life as a parachute designer and skydiver. I designed five days a week and jumped on the weekends. I was both the designer and end-user of the product. I have always felt that people who design products should be condemned to use them. ☺

See the "[Dan Poynter's Eternal Friends of Skydiving](#)" interview (YouTube video) and the "[Dan Poynter: He's done it all](#)" slideshow presentation.

Goals give us something to live for. For you it may be family, religion, or some other reason to survive. For me it was this book. Writing, publishing, and supplying it to people who need this information kept me going. With research, I drafted most of the book and actually looked forward to being admitted to the hospital for the procedure. For me the transplant was not a torturous ordeal, it was an exciting adventure. And I hope you understand that I'm researching and writing this book for you. Only with the experience of going through the procedure could I gain the information needed. The book project supplied both hope and perseverance. Your goal, whatever may be, will keep you going through the tough days.

This is not a medical text. It tells about the adventure you and I share. Having been there, I know your concerns and what you will face. I wish this book had existed when I was diagnosed with Chromosome 19 trisomy and was looking for information.

Share this book with your donor and primary caregiver.

This book is written to answer many of the questions you will have. You will learn more about your blood than you ever wanted to know. You will benefit from my research plus my day-to-day experiences. The research tells you when and what should happen while my personal experience is my day-by-day account. You'll benefit from both.

This book is not the last word on stem cell transplants. Ask your doctor, nurses, and other healthcare professionals. Do not be afraid to ask. Answers are reassuring.

The Procedure You Will Follow

- Insurance benefits verified
- Paperwork, mostly liability waivers
- Testing of patient to determine if a transplant is needed
- Testing of patient to verify you are healthy enough for a transplant
- Deciding which treatment is the best one for your condition
- Selecting a transplant center; ask your local oncologist.
- If allogeneic, testing of potential donors and looking for a tissue match

- Donor pre-screening physical exam
- Donor stem cell mobilization
- Donor stem cell collection via apheresis
- Patient admission to hospital
- Getting your transplant
- Moving to post-transplant housing
- Going home

Momentous Occasions

During the transplant procedure you will go through several gates. Each one is a momentous occasion. You will look forward to them and will celebrate them.

- Finding a qualified donor
- A successful transplant
- Being disconnected from the IV pole
- Permission to use a real toothbrush
- Release from the hospital
- Release from post-transplant housing
- Release from the restricted diet
- Off of IV medicines
- Removal of the CVC or “port.”
- Off of pills

Location of Your Transplant Procedure

The location of your transplant center may depend upon insurance company dictates and/or the medical problem you have.

For a list of hospital options see

<http://www.bmtinfonet.org/transplantcenters>

This book references the UCLA Medical Center where I underwent my procedure. You will find Internet connections to UCLA maps, parking information, food, and much more. If you are being treated at another facility, make Google searches for similar information

Map of UCLA:

http://maps.ucla.edu/campus/?cat_id=8

After transplant, your quality of life should improve. It should be as good or better than before. Transplants are not always 100% successful but they have prolonged the lives of thousands of people.

**“Dying right now is not an option,
I have more books to write.”
—Dan Poynter**