

JOURNEYS WITH A THOUSAND HEROES: A CHILD ONCOLOGIST'S STORY

John Graham-Pole

 $\begin{aligned} Wising \ U_p \ P_{ress} \ Collective \\ Wising \ U_p \ P_{ress} \end{aligned}$

Wising Up Press P.O. Box 2122 Decatur, GA 30031-2122 www.universaltable.org

Copyright © 2018 by John Graham-Pole

All rights reserved. No part of this book may be used or reproduced in any manner whatsoever without written permission, except in the case of brief quotations embodied in critical articles or reviews.

Catalogue-in-Publication data is on file with the Library of Congress. LCCN: 2018947694

Wising Up ISBN: 978-0-9826933-4-6

CONTENTS

INTRODUCTION	1
CHAPTER 1: LEAVING	3
CHAPTER 2: JOURNEYING	27
CHAPTER 3: MAKING FRIENDS	47
Chapter 4: LEARNING	65
Chapter 5: CLIMBING	97
Chapter 6: VENTURING	125
Chapter 7: GROUNDING	147
Chapter 8: CREATING	177
Chapter 9: HOMECOMING	201
ACKNOWLEDGMENTS	227
DISCUSSION QUESTIONS	229



INTRODUCTION

A line from a letter my mother wrote me when I was twelve, two weeks before she died: "Johnny-Boy . . . I think you will choose medicine." Her death inspired my life with children with cancer, who became my mentors and companions on my journey to reclaim—as did Dorothy in *The Wizard of Oz*—my full intelligence, heart, and home. The great irony of my life is that I wasn't to read her prophetic words until after my retirement more than fifty years on.

Witnessing the sacred moment of birth and first breath of a newborn during my medical school obstetrics rotation, holding the still beating cord in my hands, sealed my enduring love for children. This book tells the stories of some of them, and of my own life of care for them. They mostly had cancer or other critical illness, and I tell their tales against the backdrop of transformation in children's oncology over the past four decades. When I graduated from medical school fifty years ago, hardly a child was cured; today, three-quarters may grow to have children of their own.

My mother's death lit the spark in me to follow a life as an oncologist. Children became my allies and mentors, and my writing comes out of the deep well of creativity and motivation my patients awoke in me. Children are artists in life and, faced with life-limiting illness, bring their creative intelligence to bear on frightening and confusing things, as they confront any manner of adversity.

I think of fourteen-year-old Joey, "prancin' and dancin', smokin' and jokin'" (his words) while he was busy dying of bone cancer. He challenged me: "Lighten up, doc, who said you've got to be so serious?" and lit my path towards a new joy in my work. Even a certain notoriety for making ward rounds in funny hats and mismatched rainbow socks, sometimes on my bike.



CHAPTER 1: LEAVING

"Don't forget the mint, Johnny-Boy. And don't eat all the peas."

The late August sun slants off the kitchen slates of our house—47 Bristol Road, Weston-super-Mare—as Mummy stoops to lift milk bottles from the back doorstep for the first cup of tea of the morning. Early sparrows have pierced their shiny silver tops for the cream: fine by me—I hate the stuff. An aroma of bacon wafts from the kitchen to my perch on a favored limestone slab by the path to the back gate. I shell the final peapod, brush six peas into the colander, pop two into my mouth (I always keep the biggest pod till last), and pluck a handful of mint sprigs, rub a leaf between my fingers as I head into breakfast.

When I had clambered onto the garage roof first thing this morning with ancient cross-eyed tabby, Flossie, I had seen right across Weston sands and the English channel to South Wales—the home of Mummy's birth. But Weston has been my home ever since we moved from Devonshire ten years ago in 1944, when I was two: an English boy, born of Scottish-Welsh parents.

I finish peeling and slicing the last potato. It slips from my grasp onto the tiles as I go to pop it into the roasting pan to join its fellows, rolling towards Mummy as she slides the joint of lamb into the oven.

"Butterfingers!"

"I think you like me dropping things, gives you a chance to use that word."

"You be sure you give it a good wash, Johnny-boy, or I'll be $\it butter fingering$ you!"

I scamper next door to the dining room to lay the table for Sunday dinner, knowing Mummy will have been careful to lay out the Wedgwood



CHAPTER 2: JOURNEYING

The words embossed on my parchment certificate, signed November 16, 1966, in an illegible hand by the University of London Academic Registrar, read: "John Richard Graham-Pole of St. Bartholomew's Hospital Medical College, having passed the prescribed examinations, has this day been admitted by the Senate to the degrees of "BACHELOR OF MEDICINE and BACHELOR OF SURGERY."

A newly branded doctor, let loose on the world. The time-honored motto duns in my ears: "You can always tell a Barts man, but you can't tell him much." It feels as arrogant today as it did when I first heard it issuing from the dean's mouth more than six years before.

I am still obsessed with banishing cancer, driven by the ache of Mummy's memory. I screw up my courage and apply for an internship under Gordon Hamilton-Fairley, Britain's first and only professor of medical oncology. I am astonished to learn a month later that my application has been successful, to be followed by a second six-month internship with Dr. Neville Oswald, one of the old breed of chest specialists. He has built a reputation developing new remedies for TB, which to an earlier generation was a scourge equal to cancer. Lung cancer is the mainstay of his practice nowadays—an added bonus to an aspiring oncologist. The only snag is that my post doesn't start till next July, so I will need to do my obligatory six-month surgery internship first. Reluctant to uproot myself from London, I apply for the only position still available—orthopedics—and they hire me sight unseen.

There is only one orthopedic surgeon, eighty-year-old Mr. J.-B., who shows up irregularly to "do the hips." My first day, Mr. S., his chief assistant, tells me the score. "Two cases max on Fridays—and expect him not to show,



CHAPTER 3: MAKING FRIENDS

Ten months into my internship on the medical wards Dalziel and Annie Zunz, I am finally finding my way around. Neville is easy enough to work for, as long as I keep his beds full and have those interesting cases for his Thursday teaching sessions. Rarely, I entice him to drop in on Annie Zunz, if I have an unusual chest case or, once, a young woman back from visiting her family in New Delhi with a flare-up of *falciparum* malaria.

She knows exactly what her problem is and simply wants a refill of antimalarials, having no G.P. of her own. Being a Wednesday night, I had prevailed on her to come in for closer observation. I even have her blood slides on Thursday morning for Neville to demonstrate the malarial parasites as he dilates on his years in the tropics. That evening, she threatens to leave AMA—"against medical advice." She looks in radiant health, and her husband is making noises down the phone in an accent unintelligible but fierce, so I discharge her with a two-week chloroquine prescription, and the fervent hope she will quickly get herself registered with a G.P.

I no longer have first-line responsibility for Gordon's patients, but Neville's urgent patients mostly have well advanced lung cancer, so I put in frequent requests for thoracic surgery consults. These are usually followed by frequent radiotherapy consults, the surgeons having biopsied the lung lesion and delivered their judgment that it is inoperable. The chemotherapy we give Gordon's patients is impotent against lung cancer, so palliative radiotherapy is all we have to offer these sad old men. Sister Dalziel knows the score all too well, and allows the ones still ambulant to head down to the square to puff their Player's Navy Cut as a kind of palliation.

I come up for air, wondering what to do next. To pursue my medical



CHAPTER 4: LEARNING

As the year draws on, I grow more and more certain of my chosen path. My weekly essays have me boning up on every aspect of children's health and illness, seeking to master as much as possible of medicine's ever-expanding encyclopedia—narrowing my focus towards children's cancer. But it's my day-and-night encounters with the children themselves that are my real learning. Their irrepressible courage and resilience, their sense of wonder and creativity, are more than a match for the limitations illness lays upon them. I am falling unreservedly for every one of them, and growing in self-confidence in the care I can offer.

Quint runs a special clinic for children with both C.F. and C.P.—cerebral palsy—some of whom have spina bifida, too. I am familiar by now with C.F., but we don't see many children with C.P. on the wards. Before the clinic starts, Quint gives us a rundown.

"To put it simply, cerebral palsy refers to conditions causing limited use and control of a child's muscles," Quint tells me. "Sight and hearing are often limited, as well as swallowing. There are many causes—prematurity, maternal infections in pregnancy, genetic aberrations—but most often we never know the reason. Sadly, many children have severe damage to their brains and not much intellectual function. Many don't live very long, or are placed in long term care facilities. We see just the ones here we feel we can help—which is the minority."

He pauses for my questions, but I am silenced.

"Don't confuse C.P. with spina bifida, though the two can certainly overlap," he goes on. "We see a good number of these children, too. With spina bifida, part of the back of the brain and spine doesn't close over



CHAPTER 5: CLIMBING

Dr. Willoughby starts talking to me about a new project. He has installed an American apparatus called a continuous flow cell separator, which occupies pride of place in the lab. It is a giant box on wheels with a stand attached behind, and loops of I.V. tubing disappearing into the business end in front.

"John, I'm most excited about this." His upper-class drawl barely contains his delight. "The procedure is awfully like donating blood, d'you see? Only we have the person's blood run straight through this centrifuge," pointing to a translucent plastic bowl inset into the box. "Then, Bob's your uncle, the blood separates in the most *splendid* way into its component parts. Red cells, plasma, and most especially, the white cells in the middle. The most elegant thing imaginable!" He pauses for my reaction.

"So we can select just the bit we want?"

"Absolutely, dear boy, you've hit the nail on the noggin!" He whirls around and beckons one of the senior techs. "Maggie, be a dear and bring one of your centrifuge tubes, one you've just worked with." He holds up the transparent glass tube she hands him. "You're of course totally familiar with this, John. You see the buffy coat right there, sandwiched between red cells and plasma?"

Sure enough, the narrow white band is unmistakable, lying between a column of red cells at the bottom and the pale yellow plasma on top. Extraordinary I never paid attention to such a commonplace thing.

"Just imagine being able to circulate the whole of a person's blood through this machine over and over again." Dr. Willoughby is almost jumping up and down in his exuberance. "The manufacturers claim you can process ten liters of blood in under four hours. More than twice an adult's



CHAPTER 6: VENTURING

I start making regular trips back to G.O.S., my old haunt. Jon Prichard is fresh from a year's fellowship at Dana Farber in Boston and has just been appointed as a full-time oncologist there. So now there are two of us in the country, and the scene looks set for dialogue and cooperation, assuming territorial rivalries don't get in our way. Having served time in the training ranks of both places—Barts and G.O.S.—I know politics can readily raise its ugly head. Easy to envision what kind of competitive instincts may emerge when two brand new pediatric oncology units open up within a mile of each other. Statistics tell us that one in ten thousand children will develop any kind of cancer, so a pretty small number will fall victim in all six home counties on any given Tuesday.

Jon welcomes me warmly. He has established weekly teaching rounds for the whole staff, but he is hoping to attract interested outsiders. There is an obvious American flavor to the set-up, and I find myself fitting in comfortably. It is a welcome relief from the very British style of our Barts conferences. These are focused entirely on adult cancers, and all they do for me is evoke grim memories of my intern year with Gordon and Neville.

I get to present Jennifer, my four-year-old patient with A.M.L., and talk about our success treating these children in Glasgow. John tells me about a plan to start a children's oncology group in Britain. John Martin, the senior pediatrician at Alder Hey Children's Hospital in Liverpool, and Pat Morris-Jones at Manchester Children's Hospital, have organized a day to explore pooling our efforts. They have both been giving chemo to children with solid cancers—kidney and bone and brain tumors—to supplement the surgery and radiotherapy that were until recently standard treatment. Several of us



CHAPTER 7: GROUNDING

The heat hits us as we step from the plane and make our way to the terminal. I am thrilled by my first glimpse of palm trees in the entranceway, set off by an array of tropical plants I can't put names to. Barbara is in high spirits, too, as we recapture our old joy and jokiness. We take a taxi to Mr. Wong's Chinese to meet Gerry Schiebler, the pediatric department's chair. There is an air of affability about the whole occasion as he introduces us to other faculty members. He seems more interested in getting up-to-date with Cleveland colleagues and exploring our family backgrounds than talking about our prospective jobs. He already has our C.V.'s, but makes no mention either of our credentials or his expectations. Lunch over, he drives us across University of Florida's expansive campus before touring us through Shands Hospital.

Our surroundings blur amidst countless lightning introductions. My afternoon passes in meetings with faculty, including Paulette Mehta, the only full-time pediatric hematologist, who is eager to have us join her. Barbara is whisked off by a realtor to look at houses that might appeal. Our appointments seem foregone, and the following weekend we celebrate my appointment as associate professor of pediatric hematology, oncology, and transplantation. Barbara is to become a full-time medical writer responsible for editing faculty and research fellows' papers and grant applications. I am already planning George and Kate's next trip, excited about exploring Disneyworld, Epcot, and the Florida beaches.

Back in Cleveland, I pack my worldly goods into my M.G.B., sell my few sticks of furniture, and bid goodbye to colleagues and friends. At my final visit to Florence, she repeats the psych tests and assures me I am in



CHAPTER 8: CREATING

I take to giving voice to my lifelong love of words—dating back to my early school years—through writing poems. Even with my first raw attempt, penned sitting through a four-hour bioethics meeting, it feels like I've passed into a garden and fallen in love with the resonance of all these beautiful flowers. I'm mostly writing requiems for my young patients, giving voice to whatever surfaced in me during each relationship. The power of scribbling a few lines on a stick-it note quickly catches me up, and I find myself creating oodles of fragments throughout the day's moments, whenever a thought or image, hectic or humdrum, strikes.

I try to capture the final moments of a nineteen-year-old patient I had cared for over the past two years, and watched die by inches over the past two months. Though it may not happen tonight, his nurse, with many years behind her of witnessing these scenarios, has summoned me from home, feeling it could happen any time. I had originally admitted Will as a brawny seventeen-year-old defensive lineman, looking at a scholarship to a Big Ten school—Michigan or Ohio State—with horrendous belly ache and intractable vomiting. A surgical biopsy showed lymphoma that had taken over much of his abdominal cavity. The craggy mass was so matted down on his gut, pancreas and kidneys it was impossible to cut it out without wreaking fatal damage to these organs. With his kidney function worsening hourly, Will, though close to death, responded heroically to our hefty chemotherapy, and a few weeks later a repeat M.R.I. showed the cancer had shrunk to a quarter its original size. But the drugs had inflicted devastating effects on his body, mind and spirit, and the once two-thirty-pound linebacker started resisting our efforts every step of the way.



CHAPTER 9: HOMECOMING

A week after my return, I get a call out of the blue that makes me feel the stars are aligning as the universe ordered them. It's from Tim Bowen, the director of Hospice of North Central Florida.

"We've decided to add a hospice dedicated to children, and we'd like you to become its medical director. What do you think? We've got twenty adult beds, covering eighteen counties in northern Florida. It's a pretty big catchment area, as you can imagine. And your work would be largely home visiting, we wouldn't expect you to admit many children here."

I have no idea how Tim Bowen got my name, but the timing could hardly be better, because I had recently initiated a conversation with my department chairman, Terry Flotte, about establishing a palliative care service at Shands, and he'd made very supportive noises.

"Thanks for thinking of me. I'd be most interested—perhaps we can get together to talk?"

Tim and Bob McCollough, the hospice's medical director, and I meet for lunch to thrash out details. Although I've never met either before, they obviously knew a good bit about me and apparently satisfied themselves I'd be the right person. A week later I meet with Terry and my hematology-oncology chief, Steve Hunger, to discuss my future in the department. As I rehearse what I want to propose, I sense a chance to build on this synchronicity of events. My growing interest in the art of care and how the arts can create a more holistic environment, mesh with everything I have come to know about the growing field of palliative care. As soon as the three of us are settled in Terry's office, I announce my interest in working full-time in palliative care. I've come fully prepared with everything I can glean about such pediatric



DISCUSSION QUESTIONS

CHAPTER 1: LEAVING

- 1. The formative experience of John Graham-Pole's childhood was the death of his mother from cancer when he was twelve—not only the death itself but also the way people around him responded to it. How was serious illness or death presented to you as a child by the adults around you? Does that experience continue to shape your attitudes about illness and death?
- 2. Did it surprise you that John decided to go to medical school when he had no intrinsic intellectual curiosity about science? Do you think of the study and practice of medicine as inspired primarily by a scientific bent? What do you think were the major influences on his decision to pursue medicine—family tradition, economic opportunity in the form of a scholarship, observing his uncle at work as a local general practitioner?
- 3. John's medical education was almost completely subsidized by scholarships. How true do you think that is for American physicians today?
- 4. Does the motto "See one, do one, teach one" make you feel secure as a patient? What are the benefits to the medical students, as doctors in training, of immediately applying the procedures they learn on real people? What intellectual and emotional skills does this approach encourage? What ones does it discourage?

CHAPTER 2: JOURNEYING

5. Many of the stories in this chapter are told, often humorously, from the point of view of an anxious, sometimes inept, young intern on a steep learning curve. How would these events have looked from the point of view of the person receiving the lumbar puncture or waiting for a successful venipuncture?