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Difficult learning

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From an education comes the ability to learn.

In Time what you remember of course work and tests here, the information of this education, will fade. If you are to remain an educated person you will need to use your education to learn.

Today wanted to make a few remarks about this next phase of your education and give some examples of *difficult learning*.

Education:

I was never an easy person to teach. I doubted, questioned, and argued my way through an unusual education. My interests in people and art, medicine and science, which are the sustenance of my work and learning each day, were fostered by a few teachers of literature, writers, scientists, and doctors. I remember them as gifted teachers and thoughtful people.

To Jim Hopkins March 1994:

Does this selection committee know that I am an alumnus who was at the bottom of his class at VES? An Alumnus who failed to get a diploma there? They will say "what you did at this school is not important." "This recognition is because of your undergraduate honors, Phi Beta Kappa, a medical degree from Harvard, an honorary doctorate, the Schweitzer Prize, your research, your work as a doctor....." They will say that, but, Jim, you and I know, for me that is the rub. My education there, at the bottom of my class, was important. An honor from the school of my scholarship and my work should in some way find value in my education there. I suppose a talk on April 15 would be my chance to say as much. My remarks may, at least, be heard by some promising student at the bottom of the class.

The talk ended with the remarks:

That I failed chemistry in high school was of no final importance. The effort to teach me chemistry then was wasted. The information and skills I now use to do research in the chemistry of diseases was gathered through reading & conversations, by work in my laboratory, in periods of quiet thought, and from the care of patients - all long after I stopped going to lectures about chemistry.

To school advisors and administrators, I say, *don't overvalue grades and class standing. Be haunted that my record at this school only shows failure, yet, my experience here was rich and important.*

(When I comment about grade cards our children always remind me that they had to sit through that lecture.)

Letter to Mary Ann Cormack Stanford University

You did make an unusual choice for a lecturer, in more ways than one. Unusual I think for a large university hospital to ask a pediatrician in solo practice in a rural area to talk about his work taking care of broken children. Few at Stanford aspire to take my place.

Unusual too in that I was not destined to be a doctor, but, I doubt you could know that just from my essay. As a young person I *fooled with fate* - in 1969 I was at the bottom of my class in high school, flunked all my science courses, left without graduating, and went off to work in the merchant marine. Ten years later I started medical school at Harvard.

Janus School: A school for children who have difficulty learning:

I began to study the violin in June of 1995 at age 45. To the horror of my wife and children I gave my first concert only one week after starting to play the violin. I had been ask to speak to the graduating class of a school for children with learning disabilities, the Janus School in Lancaster. I played the theme from Dvorak's *New World Symphony* and was able to convince them that we can all be shown to have learning disabilities if given the right test or task.

In my class at Harvard Medical School there were many students who had never failed a test, some had never made a C on a test. Most of my classmates were there because they were extrordinarily successful at schooling. *If experience with test failing ihas any educational advantage I can tell you that I was way ahead of them.*

In my work as a physician I confront the limits of knowledge daily. Failure is a constant companion. *Failure* is part of learning and signifcant earning is difficult.

Any person who does not have difficulty learning, is not trying to learn anything very difficult.

The ability to learn evolves in time. I can learn, I will learn, things now that 10 years ago, 30 years ago I could not or would not, learn. No doubt this in part is because my interests, my responsibilities, the conditions under which I work, have changed so much but I find that as my interests evolve so do my aptitudes for learning.

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Cello

There is a remarkable difference between listening to the cello solos of Sebastian Bach and learning to play them. I encourage you to pick-up a cello, bow, and score and think about that difference. Think about the sustained effort to learn the Bach cello suites.

J.S. Bach from the Suites for Solo Cello, play the Sarabande of Suite V.

Difficult learning. The Suites for Solo Cello were written by J.S. Bach between 1717- 1723. Before Pablo Casals began to play the Suites the music had been largely forgotten and had probably never been played in concert in their entirety. The Bach Suites for Solo Cello are printed on 35 pages and contain approximately 360 lines of music. Pablo Casal's recording of the complete Suite runs for 2 hours and 10 minutes.

Casal's first saw th Bach Suites when he was 13 years old, he studied this music every day for 12 years before playing parts of the suites in concert. He had worked with

the music for 35 years before he finally agreed to record the complete Suites.

I have studied the four lines of the Sarabande of Suite V for more than a year. The lines are played by Casals in 2.8 minutes and by Yo Yo Ma plays in 3.5 minutes. At my rate of learning it will take me approximately 35 years to learn the Suites. In reality, much of the music will always be for me unplayable. *Difficult learning, yes.*

I study the cello. I work at the cello - I practice an hour or more each day. I read about the history of the instrument and its music. I study a book called *Cello Technique* by Gerhard Mantel which examines the physiology and anatomy of cello playing. I read about the physics of stringed instruments in books such as *Science and Music* by James Jeans. I study the cello just as I study medicine. For me the learning process is the same. MSD: I care for 70 children with an inherited disorder called maple syrup disease. Elsewhere this is a rare disease, those 70 patients represent the largest group of patients in the world. Over a ten year period I have worked to care for these children and understand their disease - emergency care, laboratory work, research, writing teaching, relearning biochemistry, relearning, endocrinology, relearning neuroanatomy. It is a safe estimate that most days I have spent at least two hours working with some aspect of this disease, many days, 18 hours or more trying to keep a child alive and limit the injury the disease causes to the brain. Studies of this disorder provide important insight into how a genetic disease affect the brain - coma, Parkinson-like movement disorders, attention deficit disorder, mental retardation. All dependent upon abnormal transport of amino acids into the brain..... Over 10 years I have spent more than 10,000 hours learning about this disease. For comparison, the average college course gives 40 hours of exposure to a subject.

But there is more than science to this work - A letter to a student

January 15, 1997 midnight. Half asleep, weary, I write as I wait for amino acids to finish running. A sample brought in by a hired driver from a hundred miles away. A sample of blood from a new baby with maple syrup disease.

He is not yet ill. His sister will be happy to have a brother to share formula with. He is the fourth child for Reuben and Martha, their first son, the second of their children with maple syrup disease. He will be well cared for and loved.

Martha 25 years old and has four children, two with this disease. How much of the next 20 years of her life will be given to this child and his trouble How many hours of my life will he claim? I always think of that as I examine a newborn with maple syrup disease or glutaric aciduria or Crigler-Najjar disease - each child takes, needs, defines another piece of my life. A few more hours from nights and holidays, a few less hours of needed rest or reading or writing or music. Meaningful work? Yes. No doubt what I know, what I have learned, helps these children. Interesting life, interesting work too. Exile too? Yes. Child by child, hour by hour as I am needed, my future is taken, decided, shaped.

Is some part of your life too claimed by the birth of this child? Unaware, have such children already begun to shape your life? Was that part of the cost of coming here,

searching for, seeing, meaningful work? Was that the ultimate cost of learning to care for such children? Can you give that much to them?

My computer has a much better and bigger memory than I do. It is a better spell checker too. It frees me from the drudgery of handwriting and makes editing easier. But the computer depends on me for the concepts that put its information to work. If there are human qualities in the computer - concern, compassion, humanitarianism - I put them there. Compassion is not part of the hardware or software.

I study writing in the same way I study the cello, perhaps for the same reason. Wallace Stegner, who is one of the writers I most admire, said the best way to learn to write is to find something you care about deeply and write about that. I have written a few stories.

The story that follows began as a story about a child with a lethal genetic disease and was at first written to express my sense of helplessness and anguish before this child and his disease. Over the years since the boy died the story has been rewritten twenty-one times. A different understanding of the care of the child has emerged.

From *Croquet*

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Oxygen and antibiotics held back death a few weeks. John died after Christmas, after his birthday, at home, peacefully.

In the summer of that year Jake and Sadie invited my family and me to supper. Jacob, Nancy, and Susie were there. Our talk often turned back to the boy *who was no longer with us*. The purpose of the day was not to forget the child but to remember him.

After supper we went out to play croquet in the meadow by the house. The wickets were placed far apart and the field was long and wide as though for some extraordinary game.

I remember our voices, the crack of hard-stuck wooden balls, the sounds of children barefoot, laughing and running through high grass of the meadow and into the corn.

I recall the songs of meadow birds and crickets mixed and diffused into evening's air and carried into the fields beyond as a kind of music and song.

I remember the great graceful Percheron mares and their colts running through the meadow, as though some part of our game, and the barn swallows turning and turning and turning against the rich summer greens of earth and blues of sky.

And, I remember the warm light of summer evening that washed over everything and over us.

When the daylight faded Jake brought out lanterns and we played on into the night each with our own small light. I thought, someone on the distant hill, watching our lanterns move back and forth across the meadow might, if she watched long enough and knew the game, realize that we were playing croquet.

From there too, she might have watched my car come and go those winter days and, if she knew the nature of my work, she imagined the sadness of my task.

When carriages gathered on the frozen meadow row by row black against snow she would have known death had come, and, watching carefully from the distance, she might learned something about the customs of Amish people at the time of death.

But there is more to know than can be learned from such distant, high places. More to know about these people, about work such as theirs and mine. More to know than just the name of a game played on a meadow one evening in summer.

More than seven years have passed since we played croquet on Jake's meadow. Jake and Sadie have another child who is healthy. My visit to first examine the new baby was a joy for all of us.

We now know the genetic and pathophysiologic basic of the boy's disease - troponin myopathy and this knowledge brings new hope and requires new learning - since 1963 there have been 6413 paper written about the role of troponin in muscle physiology. In this old literature there are new questions and new answers a renewed need to learn.

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I have been told that special children are gifts from God. I have been told that special children are punishments from God.

I have heard scientists and doctors refer to these children only in terms of their genetic defects, aloof and with no human insight, as though the life of a child can be reduced to such terms.

My experiences have made me think in a different way about these children and their short, often difficult, lives.

I cannot say why these children come and go upon Earth but I do know that they change the lives of those who know them.

Such children have been my most important teachers. I have learned more from them than I did from many instructors at Harvard Medical School who were by reputation great teachers.

These children have reshaped time and again the way I practice medicine, both the science and the art of it.

I have heard sermons by ministers about compassion, I have heard fine lectures about ethics and medicine, but no sermon or lecture has taught me as much as a single special child.

These little children change whole communities of people in ways that last far beyond their brief lives. They are not merely the focus of compassion but are often compassion's very source.

Special children enrich the world in ways that many who are blessed with longer lives do not.

They have much to give us, to teach us, about themselves and about ourselves.

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The end of the story also brings me to a notion that I most want to leave you with is that *the important experiences of your lives, that will shape questions you ask, that will make you the person you will become, are today unknowable, are at this time in your lives unimaginable.*

The night I went to see John Ray, the boy in Croquet with this unnamed deadly

muscle disease, I was tired and reluctant to go. I felt so helpless before this child and his disease. I was helpless.

An understanding of the importance of the time with that child came slowly, with much effort - as does the music from my cello. Difficult learning....

William Carlos Williams physician and writer said (in our work) - *We catch a glimpse of something, from time to time, which shows us that a presence has just brushed past us, some rare thing ... For a moment we are dazzled.*

In the next few years of your lives, watch carefully, listen carefully, search carefully for meaningful experiences. Search for meaningful work. And, most important, use your education to learn.

Finally, if you want to play the cello - don't wait too long. *Difficult learning*, such as cello playing, does not in time become easier.

dhm 5/20/00