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Accounts of an Illness:

Extracts

Ron Schreiber, Ph.D.

The following pieces, with an introduction by the author, are from a work in progress entitled John, to be published in the fall of 1988 by Hanging Loose Press and Calamus Books, New York City. In this work, Ron Schreiber, John's lover of nine years, writes a chronicle of a terminal illness from diagnosis to death.

John MacDonald, Jr., was born in Dorchester June 10, 1951; he died in Holbrook, his parents' home, November 5, 1986. John graduated from Holbrook High School, attended Northeastern and graduated from the University of Hawaii with a degree in marine biology. He had done various things in his teens and 20s, since he was kicked out of his parents' home by his father when he was 15 (for being gay). He'd done a nightclub act in New York, cut demo records, modeled, worked as a geisha in Kyoto for three months. He worked for some years for New England Telephone Company and for many years for Winston Flowers on Newbury Street in Boston. He arranged the flowers for the 100th Anniversary of the Boston Pops. But his passions were plants — he planted whole gardens, grew orchids and camelias — and animals — he had three chows and two shih-tzus, five cats, a blue-and-gold macaw and many lesser birds and fish. He'd been cross-pollinating flowers since he was five.

— Ron Schreiber

Dr. Ron Schreiber is chair of the English Department at the University of Massachusetts at Boston.

protocols

so now the test is back:
positive. no surprise.

“maybe that qualifies you
for a protocol,” I say.

“I’ll get disability,”
John says, either way

he’s qualified. he’ll be
home in two days — medication

oral. Dr. Tagliaferro
mentioned “control groups,”

an easier term than protocol.
but John doesn’t like the

idea of being used as a
guinea pig. or the possible

side effects, which, he says,
could kill him.

but what
if he says yes? is hope
a chimera without even a

gold ring in its nose?
or is it possibility, slowly

creeping through a crack in
the stone door, wriggling

its slimy body into a
kind of tentative life?

your life

right now it’s all I care about
& you’re going to lose it

(wrong head, I know, but it’s
late & I’m scared & tired).

first there’s your health: I
want you to have it. you were

exhausted & sun-dazed when I
brought you back from the hospital

— after stopping to get your drugs —
& you were sleeping when I called

downstairs just now. I am tired
beyond anything my body tells me

is fatigue. & when you’re sick,

when I look into your tired, lovely
eyes, I want you well. right now

I’m trying to find the railroad cap
I lost on the long flight wait

in Florida last winter (when I was
there & you were home & healthy)

& put it on my head firm & screw it
on. I want you to get back your

health or at least its shimmering
surface. right now.

4/16/86

4/18/86

Sunday morning 4/20/86

John got out of the hospital Thursday morning. We did not know whether he'd be able to leave or not, since his white blood count was low Wednesday night, and they had to get the results of another blood test Thursday morning. They called the lab for results, and got them at 10. OK — so we left.

The sun hurt his eyes coming home. We stopped at the pharmacy to pick up his drugs, and they were expensive: over \$100. for four prescriptions. When we got home he was very tired and he was nauseous again, but John noted that his first day out was bad the first time he came back from the hospital, two weeks ago.

When John came upstairs Friday morning, I was momentarily elated: he must be better, I thought. But that was not the case: his fever had returned, the rash had begun again, and he was very weak. While he lay on my bed, I kept trying to reach his doctor, who was not in yet. The intern, Steve Boswell, called about an hour later, and told me to bring John in. Then, as John was walking down the stairs, the phone rang again, and this time it was Nettie Tagliaferro, his doctor, and she said to bring John in.

He was very bad when we reached the emergency room, and I was unwilling to leave until I thought he would be all right. I left about 11, and went into work, as I had done the day before. This time they will keep John two weeks, although apparently the new drug they are using could be administered on an outpatient basis; we would come in for an hour every day. But John does not want that, and I don't think I could stand it.

When I talked to Steve Friday afternoon, he asked me how I was doing. — Not very well, I said, though also, — as well as can be expected, I think. I asked Steve whether it was life-threatening this time, and Steve said no, not this time. We talked a little about protocols. — I want to be with John when he dies, I said. Steve assured me that they would call me right away if anything should happen.

But this time they think it will be all right. We don't know yet what the side effects of this drug will be. Probably we will have to wait ten days and then find out. So far, whenever there are potential side effects, John gets them. They just have to keep trying new drugs. Probably the rash, though, is not a side effect (though it could be), but another opportunistic disease.

Last night I slept nine hours, from 9 to 6; I had also fallen asleep in the afternoon. I am still tired this morning. I hope I can use each weekend to recuperate, for my job is very busy. This is only the second day of a three-day weekend, so I can't tell yet whether the weekend will be long enough. I may have to live with this fatigue. But that is not so difficult as what John has to do, which is to live with his various illnesses and side effects as long as he wants to, as long as he can.

back in

Saturday I waited for the plumber
all morning, & he came at one, but

I'd left the door open & visited
you in the morning. yesterday I

came by twice, & in between got
potting soil so Sue could put up

the plants we'd ordered & dog &
cat food for your larger animals.

today I'm waiting for the extermi-
nator & trying to read the book

I'm teaching tomorrow. when I come
by this afternoon it will be mask

& gloves & paper gown again, not
because you're contagious but for

fear of what I might bring in,
your white count down again.

we'll relate to each other as if
you're living, we said, but this

way it's hard; you in the hospital
& very sick, your whole attention

focused on your body & your illness.
sure, you're living, but I get left

out of the equation, except for job
& chores, the structure of routine,

& thinking of you, thinking of you
all the time.

moving towards memory

what scares me most is that the
virus often goes to the brain.

such a sharp mind, tongue like
a razor, but beard now unshaved

for weeks. then, yesterday (so
soon), John could not remember

the end of a sentence he'd begun.
at noon, when he seemed to be

miserable from the blood samples
of the morning; in the evening

when his left arm was swollen.
it's happening fast, but this

part is — now at least — more
gentle than I'd expected, like

waking from calm sleep, too
early to be able to piece

sentences together, or remember
what it was one wanted to say.

4/22/86

4/21/86

still alive

he slept through the night:
four to eight — no pain

when he sleeps. I slept:
eight to eleven; eleven

to three; three to four;
up at six. worked.

typed two documents,
played solitaire. mailed

letter at the corner
store, where I got cig-

arettes but no paper
(they didn't have one).

came back. played soli-
taire. till John screamed

just now, & I gave him
a morphine capsule.

he's on his stomach.
wet? I don't know; I

didn't turn him over.
I love you, he said.

I'd said that to him
first, and — let it go now;

I'm all right. I *am*
all right, whatever

that means. it means
ready. & I told him so

& he understands me. it's
time for the others to

tell him too.

10/25/86

10/29/86

I tried, last weekend, to convince John's sister Nancy and his parents, John & Lucille, to give John the peace & the encouragement to die. With Nancy it was clear; she could not wish it. His father said, "We don't think that way. It's God's will." "Fine," I said, "but let John know that you accept it either way." No luck. I lost the argument.

I did convince his mother, who is a home health aide, to come both weekend days. I was glad Lisa was not available. When I was out on errands Saturday morning, a decision was made to which I was asked to acquiesce: that John would go home with his mother (to his mother) in Holbrook. "That's what John wants," they said. And "we had been thinking about it, but we didn't want to say anything until Johnny said something." Not to me either, who had no notion what they had been thinking about. (The house queer; the house nigger. He's done his job — back to the family into which he was born.)

How could I tell what John wanted. He has been alert these last three weeks only for visitors. To Lisa he says, "I want to die." Sometimes that's what he says to me. Friday night he slept 16 hours. 20 hours Sunday night, when his family had gone.

Tuesday morning I was able to determine that John does want to go. The result is OK with me. We've done our closure really. We love each other.

It's Wednesday now, 9:30. His parents will be here soon. Lisa is here now. Gail has just arrived. I'm doing a laundry. The ambulance is coming at 11 to take John to his parents' home.

how did it end?

when they carried John out of the house (on his way to Holbrook) he

looked up at me as they put him in the ambulance & screamed "Ron! Ron!

Ron!" then they closed the doors, his mother with him, & drove off.

what happened next?

John went to Holbrook, where they set him up in a hospital bed. On

Thursday I visited. the nurse asked me to help her turn John over,

though his mother was there, & trained, as I was not. by Saturday his mother

was less helpless, more in charge. his father was pleased to have John

(who was not queer, who had acknowledged Jesus) home & smiling at him.

what else happened?

Wednesday morning, before his family arrived to take him "home," John said

to Lisa: "look after Ron because my family surely won't."

how did it end?

I visited the third time on Tuesday, & spoke with John. when I left the

room to drive home, Nancy went in, but John had already fallen asleep.

11/4/86

how did it end (2)?

I wasn't there. twice before — when John was home with me —

he'd slept a long time: 16 hours, 20 hours. the second time

I'd called Lisa — how do I know if he's died? I asked. & she told me.

I was at a meeting when the call came. Mary, my secretary, came in & signaled

to me. I knew what it was.

Gail was there. his mother was there. John had not awakened but Gail was

talking to him. "I have to go in ten minutes," Gail said. & then

John's hand went limp as she held it. John's mother did not realize, though

she held his other hand. "he's gone," Gail said. & he is.

11/5/86

Ron Schreiber's poems first appeared in *Radical America's* "Facing AIDS," a special issue devoted to AIDS. Copies of this issue are available for \$3.95 from *Radical America*, 1 Summer St., Somerville, MA 02143. A subscription to *Radical America* is \$15 per year.