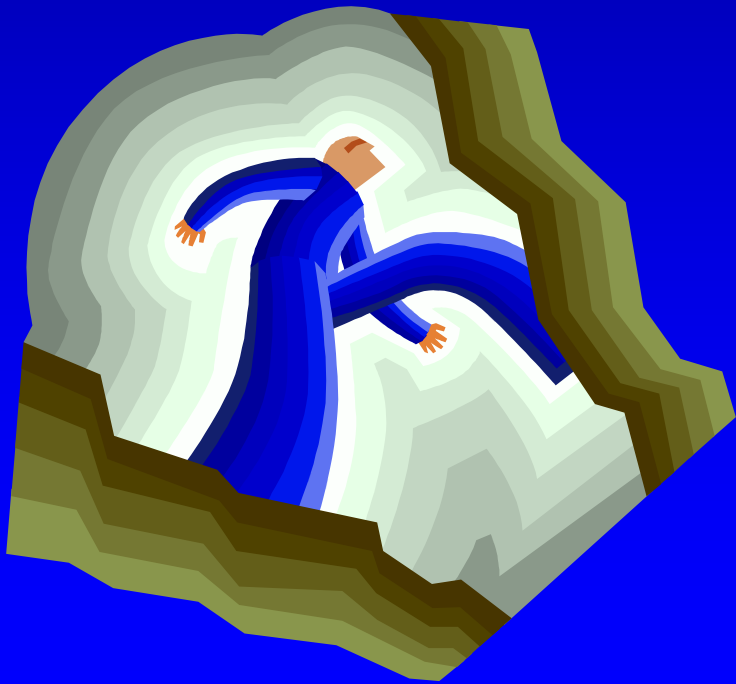


# The Experience Of Disability As Expressed Through Literature and the Arts

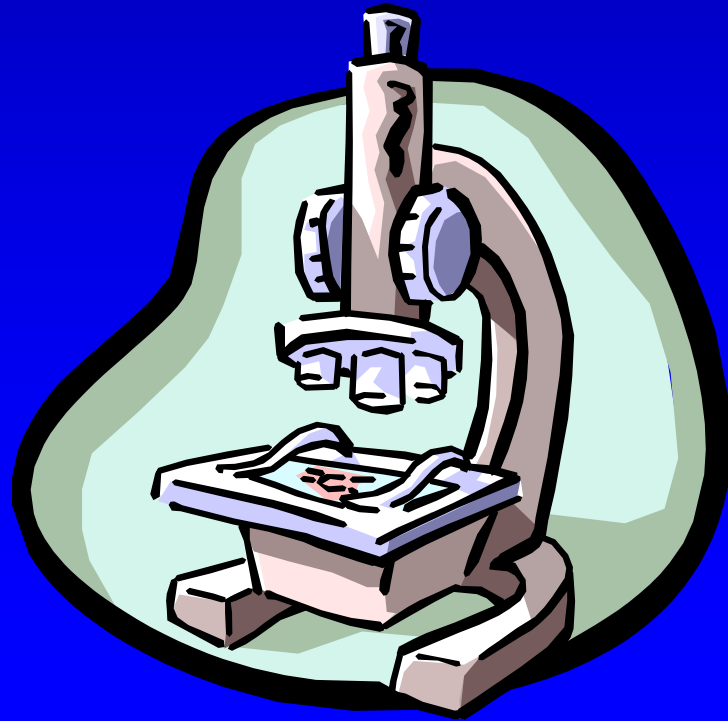


**Johanna Shapiro, Ph.D.**  
**University of California**  
**College of Medicine**  
**April 21, 2001**

# Why Literature?



# **Students Must Learn Technical And Informational Knowledge**



*Where is the wisdom we have lost  
in knowledge?*

*Where is the knowledge we have  
lost in information?*

- T.S. Eliot

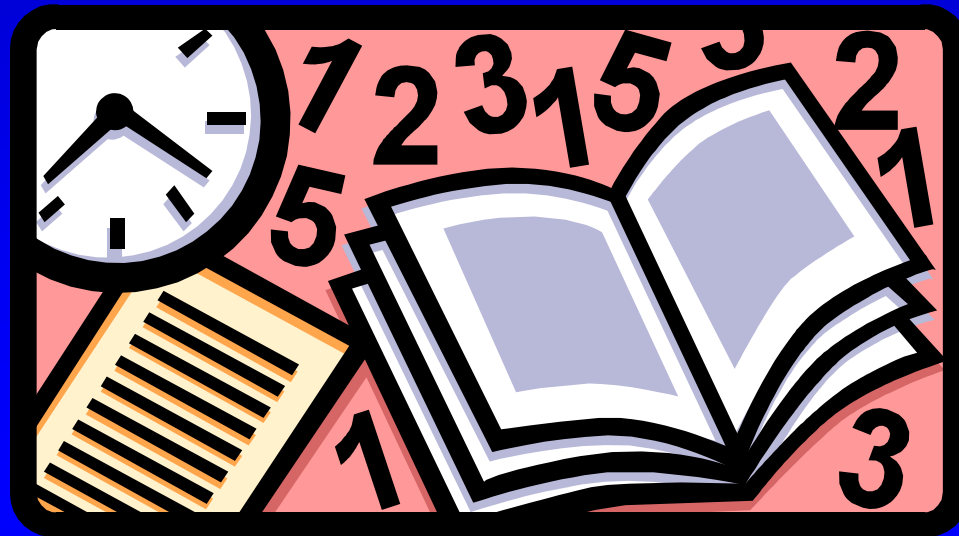
# **Students Must Also Learn Different Kinds Of Knowledge**

- **Appreciation for other perspectives and points of view**
- **Understanding of illness within the context of the lived life of the patient**
- **Ability to listen as well as talk to the patient**
- **The capacity for empathically imagining the patient's experience**

# Literature Can Be Useful In Conveying “Hard-To-Teach” Clinical Competencies



# Why Is Reading A Poem Or Short Story Different Than Reading A Journal Article?



SCIENCE CAN ONLY  
ASCERTAIN WHAT IS,  
BUT NOT  
WHAT SHOULD BE

- Albert Einstein



# **Two Modes of Thinking:**

**logico-Scientific**

**and**

**narrative**

**QUESTION:**

*What is truer than the truth?*

**ANSWER:**

*A good story*

- Jewish proverb

# What Is Important About Experience?

(How Can We Best Understand the Patient's Reality?)

**Logico-scientific:** particulars of personal experience are eliminated in favor of abstractions, generalizations, systems of classification and diagnosis

**Narrative:** emphasis is on particulars of individual experience

*We do not see things the way  
they are*

*We see things the way we are*

- Anais Ninn

# Whose Point Of View and Voice Are Important?:

**Logico-scientific:** patient's point of view is subjective, therefore suspect; patient's voice disappears from the medical record

**Narrative:** patient's point of view and voice are essential; multiplicity of voices in clinical encounter recognized

*NOT EVERYTHING THAT  
COUNTS CAN BE COUNTED*

*- Denis Burkit, M.D.*

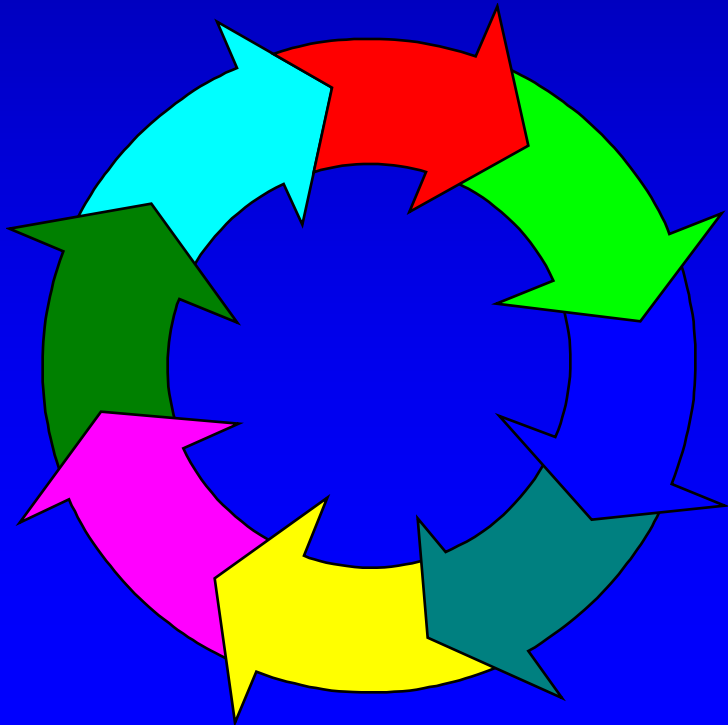


# How Should We Position Ourselves in Relation to the Patient-Other?

**Logico-scientific:** emphasis is on objective stance, detachment, distance in professional relationships

**Narrative:** requires emotional engagement and presence in professional relationships

Whatever is real has a  
meaning



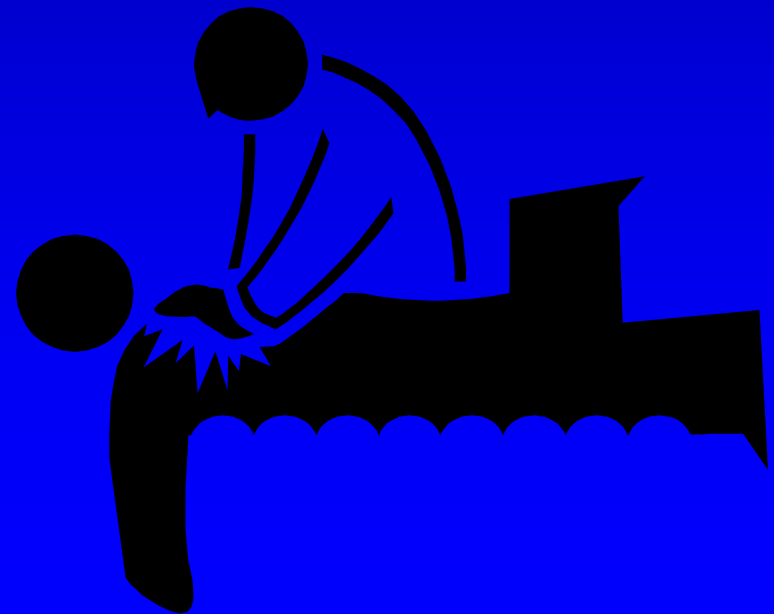
- Michael Oakeshott



# Why Study Disability?



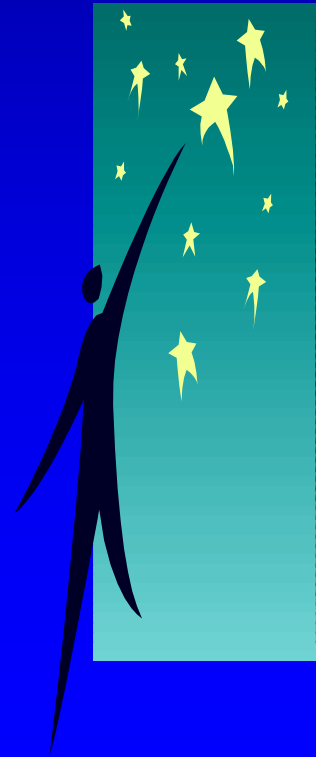
# An Unglamorous Aspect of Medical Practice?



*Doctors...may have trouble dealing with patients [with disability], whose disease in its intransigence defeats their aims and mocks their skills.*

-Nancy Mairs

# Disability Studies as Metonymy



**What are some important  
health provider-patient  
issues that can be  
approached through  
literature?**

# **Disability as Otherness**

- **Psychological function of otherness**
- **Societal function of otherness**







**What is Normal?**







# The Handicapped

1. The missing legs  
Of the amputee  
Are away somewhere  
Winning a secret race.

2. The blind man has always stood  
Before an enormous blackboard,  
Waiting for the first  
Scrawl of light,  
That fine  
Dusty chalk.

3. Here  
The repetitions of the stutterer,  
There  
The flickering of the stars.

4. Master of illusion,  
The paralytic alone moves.  
All else is still.

5. At Creation,  
God told the deaf,  
"Only you will hear  
The song of the stone."

6. Dare not ask  
What the dumb  
Have been told to keep secret

7. When the epileptic  
Falls in a fit,  
He is ascending  
To the heaven of earth.

--Philip Dacey



**Emptiness**  
**... and Fullness**

# *Fingers, Fists, Gabriel's Wings*

*My voice, plucked from the air,  
clasped in the interpreter's hands:  
fists bloom, close,  
pulse of hothouse flowers;  
supple fingerpuppet dancers  
move to unsounded strains*

*Watching the deaf girl listen,  
I think there is more to words  
than sound ever knows,  
brimming handfuls of speech  
tempered by secondhand grace.  
The word, unutterably, made flesh:  
Fingers flutter, hover, fold,  
The whisk of Gabriel's wings.*

*--Michael Cleary*

**It's art baby! art!**





*Loss...*

# Stroke Patient

Someone came in to ask  
how are you

only I couldn't  
quite hear the words,  
I thought he was asking  
who. who are you?

so I started to say  
my name's Jordan  
only I never  
got past the vowel

I'm Joe  
just Joe  
call me Joe

then I stopped to think  
maybe I really am  
someone else  
maybe all this never  
happened

my friend looked so strange to me  
till I felt his hand—  
his hand took mine  
and my hand shook.

--ROCHELLE RATNER



That Treacherous Less-Than-Human/  
More-Than-Human Continuum

# Spastics

They are not beautiful, young, and strong when it strikes,  
but wizened in wombs like everyone else,  
like monkeys,  
like fish,  
like worms,  
creepy-crawlies from yesterday's rocks  
tomorrow will step on.

Hence presidents, and most parents, don't have to worry.  
No one in congress will die of it. No one else.  
Don't worry.  
They just  
hang on,  
drooling, stupid from watching too much TV,  
born-that-way senile,  
  
rarely marry, expected to make it with Jesus,  
never really make it at all,  
don't know how,  
some can't  
feed themselves,  
fool with, well—Even some sappy saint said they  
look young because pure.

--Vassar Miller



The ill person may not feel like acting good-humored and positive; much of the time it takes hard work to hold this appearance in place.

**--Arthur Frank**





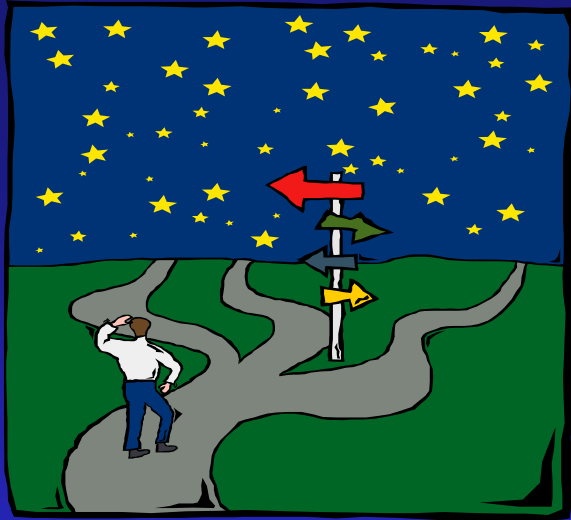
I have come to realize how distorted and unrepresentative the success stories really are...if we fail, it is our problem, our personality defect, our weakness...To emphasize individual personal qualities as the reason for success in overcoming difficulties is self-serving for the individual and society.

**--Irving Kenneth Zola**



# The Health Provider-Patient Relationship





Isolation

vs.

Community



**Dr Crazitis Crippus on her UK Crusade  
to Heal Grotesque Attitudes and  
Gruesome Environments**



# Stages of Suffering

- **Chaos and Isolation**
- **Lamentation**
- **Solidarity with others**



*Solidarity in the  
Professional Relationship*



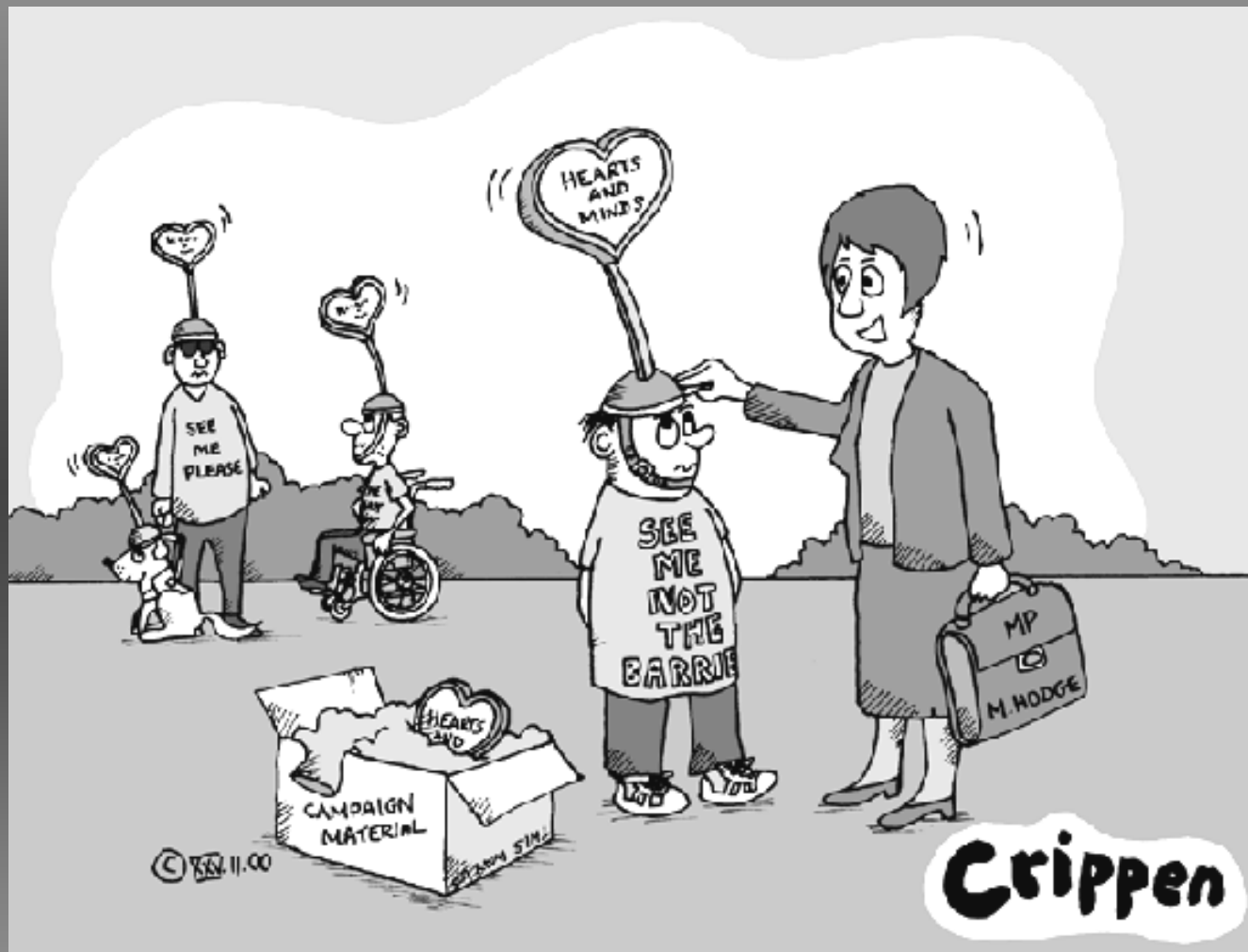
## IRENE

After the third stroke,  
her words fell off  
to a few soft syllables.  
When I enter the room  
and enter those red-rimmed eyes  
that can't help  
looking toward the left,  
she cocks her jaw  
and her cheekbones swell.  
With what looks like weakness,  
she wobbles  
her left hand to my wrist,  
but that grip  
is the grip of a woman  
who clings by a root  
to the face of a cliff.  
When she speaks, her words  
are small stones  
and loosened particles  
of meaning  
that tumble to their deaths  
before my ear  
is quick or close enough  
to save them. Irene,  
tell me again, I say,  
after the words  
in her bits of chopped breath  
are gone. But George  
takes his cap from my desk  
and puts it on his head, and says  
Her gulps don't make no sense.

--Jack Coulehan

# Learning To See More Clearly





*“We all have disabilities,  
only some of us don't  
know it”*

*--second year medical student*

## *Protect Yourself From This*

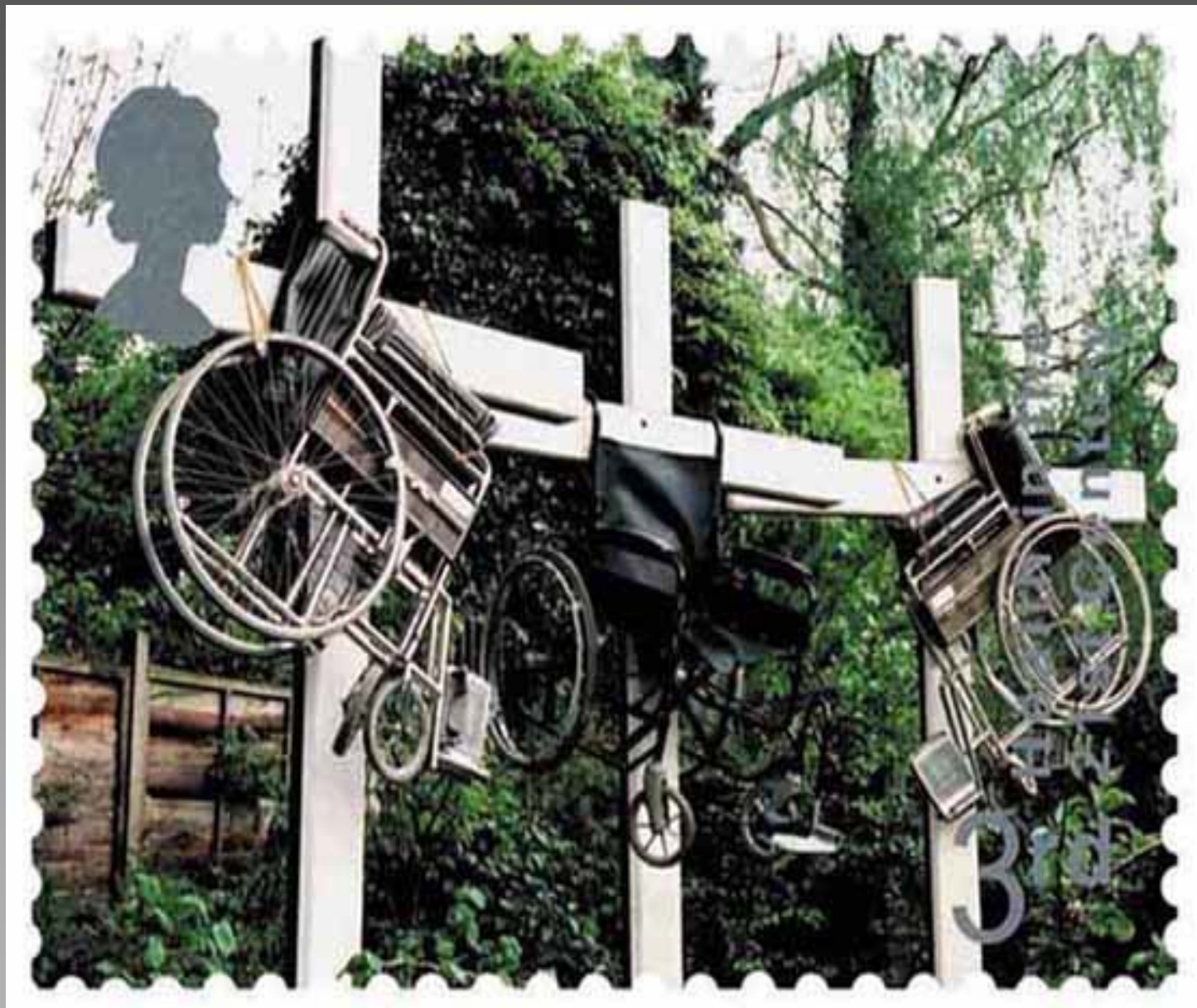
*Protect yourself from this, the sight  
of the lumpish woman in plate glass  
laboring to push herself along  
in her coat, in the sun.*

*She looks to be a woman of a certain age,  
a nice woman, but forlorn, with too much pain  
in her face to be outdoors. You look away,  
then swiftly back, to see her struggle with the chair  
outside the heavy bank door, holding her packages upright  
in her lap with her teeth.*

*She starts to mutter, how difficult  
things are. For an instant you allow yourself to feel  
her dread, her effort not to become  
another crazy crying on a Berkeley street.*

*She is not what you feel yourself to be,  
but what you see you are,  
reflected in the world's unyielding surfaces.  
You know that you can never leave her, now.*

**--KAREN FISER**



# Learning from the Other



“Close your eyes now,” the blind man said to me.

I did it. I closed them just like he said.

“Are they closed?” he said. “Don’t fudge.”

“They’re closed,” I said.

“Keep them that way,” he said. He said,

“Don’t stop now. Draw.”

So we kept on with it. His fingers rode my fingers as my hand went over the paper. It was like nothing else in my life up to now.

Then he said, “I think that’s it. I think you got it,” he said.

“Take a look. What do you think?”

But I had my eyes closed. I thought I’d keep them that way for a little longer. I thought it was something I ought to do.

“Well?” he said. “Are you still looking?”

My eyes were still closed. I was in my house. I knew that.

But I didn’t feel like I was inside anything.

“It’s really something,” I said.



