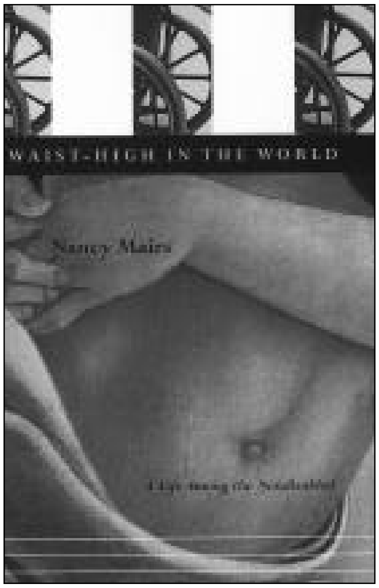
BEACON PRESS DISCUSSION GUIDES
for Unitarian Universalist Communities

Waist-High in the World

A Life Among the Nondisabled

NANCY MAIRS



A LEADER'S GUIDE

BY JULIA WATTS

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Waist-High in the World: A Life Among the Nondisabled
by Nancy Mairs
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Leader's Guide
by Julia Watts

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INTRODUCTION

On the surface, disability may seem a surprising topic for conversation, particularly among people who don't consider themselves disabled. In opening *Waist-High in the World: A Life Among the Nondisabled*, Nancy Mairs tells readers that "in embarking upon this book about disability, I have committed myself to spend months contemplating issues and experiences that mark mine as an undesirable, perhaps even an unlivable life." (p. 4) Yet through Mairs' work and through our own reflections on disability, illness, human frailty and human adaptability, we can come into a deep encounter with the power of human compassion and relationship, the potential for human resilience and resourcefulness amid change with our own bodies and our spiritual lives.

For some of us, disability may feel distant, an uncertain and possibly fearful category which implies difficult questions about mortality and human frailty. Or disability may be close to home—embodied by friends, parents, siblings or acquaintances. Disability may seem burdensome, simply human or disturbing; full of unexpected grief and also unexpected beauty.

For others, disability is an ongoing experience, a continuing process of adaptation, creativity, loss and adventure. Disability may be a source of pain, and also a source of pride. It can represent a struggle with the body and a struggle with an inhospitable world. It can also involve an ongoing sense of surrender, a willingness to encounter surprise. Disability can be feisty, frustrating, ordinary and insightful.

In *Waist-High in the World,* Nancy Mairs shares her own insights on the nature and meaning of disability in her life. Her essays invite us to grapple with her, to be challenged and to be changed by her testimony. Whether or not we know disability in our own bodies, thinking about disability can bring us into a more fully human encounter with the meanings and deep necessities of life.

This discussion guide aims to create a framework for Unitarian Universalist discussion groups to share ideas about:

- ☐ the uniqueness of our own bodies and our own resources for adapting to illness, disability, change and loss;
- ☐ how the constructed world creates problems for certain people, who we commonly call people with disabilities;
- ☐ the challenges and spiritual benefits of giving and accepting care; and
- ☐ supporting and respecting people with disabilities, as well as acknowledging our own potential for living with a disability.

This program encourages the reflections and contributions of all people, whatever their experience with disability. We hope it will foster meaningful conversation between people with and without disabilities, providing a space to explore the complexity and creativity of human life.

GETTING STARTED

Promote the Program

Many congregations have a number of resources for publicizing new programs in the community. It is always a good idea to create flyers and post notices on bulletin boards and in newsletters. Announcements during meetings and services help spread the word. Some congregations promote new programs by organizing "Kick-off Sundays," which include a sermon by a minister or lay leader about a related topic.

You might consider targeting specific groups to embark on this journey. For example, discussion groups or support groups for people coping with illness might have particular interest in this program. The program might be an opportunity to expand your relationship with outside groups or encourage other people to investigate your congregation. People at local disability organizations or independent living centers might be interested in the program, even if they aren't members of the congregation.

Adjust the Format as Needed

This program includes reading, reflection and participation in three two-hour discussion sessions. We recommend a group size of no more than ten people. While the discussion guide offers specific questions, readings and activities, feel free to adapt the program to your own needs. You can substitute your own questions, adapt those that are provided here and add thoughts of your own.

Provide a Comfortable Setting

Hold the session in a comfortable, well-lit setting, preferably with cushioned chairs arranged in a circle. Some discussions will be carried out in small groups of 2-4 people, so it is important to find a space that will enable uninterrupted discussion for small groups as well as for the larger group. The discussion sessions call for information to be recorded on newsprint, so you will need adequate wall space or easels to display what has been written. You might ask volunteers to provide refreshments and perhaps a light snack.

Hold the sessions in a room that is wheelchair accessible. When people register, it's a good idea to ask them if they have particular accessibility needs. When you promote the workshop, tell people that you will do your best to accommodate their accessibility needs (such as large print materials) if they provide advance notice. Offer to strategize solutions with them.

Involve the Group in Setting the Tone

The group should take responsibility for creating an environment that is welcoming and conducive to open dialogue. Bring to the group's attention the importance of active listening, thoughtful responses and mutual respect. Also, note that occasional silences are acceptable. Use people's own experiences as a way to ground the discussion when it threatens to become too abstract.

Some people have a tendency to be more vocal than others. If a few people clearly dominate the conversation, you might need to open a space for those who have not had a chance to speak to do so if they wish.

As a discussion leader, it is important to establish a balance between too much control and too little direction. It will be important to be responsive in your leadership and draw people out, yet keep the discussion on track.

We suggest that the group draft a set of ground rules at the beginning of the first session, post them on newsprint, and review them at the beginning of the second session. If all participants give input, everyone will be accountable to the group's needs. Common ground rules include:

- ☐ maintain confidentiality—don't repeat personal stories outside of the group;
- ☐ make personal ("I") statements—don't speak for others;
- ☐ give full attention to the person who is speaking; and
- ☐ turn off pagers and cell phones during the program.

Prepare for the First Session

Ask participants to read Nancy Mairs' *Waist-High in the World: A Life Among the Nondisabled* in its entirety before the first session. Encourage them to keep a journal of their thoughts and reactions while reading the book, or to spend some time in reflection based on passages they found memorable. Let them know that throughout the program, they will be encouraged to bring in their own life experiences as well as to reflect on the life and insights that Mairs' describes.

Evaluate the Program

Two evaluation forms are provided in the last pages of this guide. Participant Evaluation Forms should be distributed at the end of the final session so participants can give feedback to group leaders. (Note that questions 7 and 8 on the form give leaders a chance to pose their own questions to participants.) Also, be sure to send Beacon Press your completed Leader Evaluation Form. We are striving to meet the program needs of UU congregations, and your continued feedback and suggestions will bring us a long way toward reaching our goal. We really want to hear from you!

SESSION ONE

Materials: Newsprint, markers, masking tape, chalice, candle, matches, UUA Hymnal (*Singing the Living Tradition.* Boston: UUA, 1993), paper, pens

Welcome and Opening Check-In (15 min.) Welcome participants, light the chalice, and thank them for coming. Make sure that everyone knows where to find restrooms, water fountains, and other necessities. Encourage people to share their accessibility needs now or throughout the program. Introduce the program, and offer time for questions. Circulate a sheet of paper so that people can write down contact information for your records.

Explain to participants that before you begin, you would like the group to establish ground rules.

Ask a volunteer to record the group's suggested guidelines on newsprint. If certain rules you find important are not mentioned, suggest them yourself. (See "Getting Started" for common ground rules.) Once the suggestions are finished, check with the group to make sure that everyone is comfortable with the ground rules.

Tell participants that every session will begin with a reflection and a check-in. The first check-in will be based on a reading from Mairs' book, below.

Near the beginning of *Waist-High in the World,* Nancy Mairs describes the book she is writing as a guidebook through

> a country to which no one travels willingly: the observations and responses of a single wayfarer who hopes, in sketching her own experiences, to make the terrain seem less alien, less perilous, and far more amusing than the myths and legends about it would suggest. (p. 6)

After the reading, ask people to go around the circle and share briefly.

Ask participants to introduce themselves and state their hopes and expectations for the program. If they like, invite them to share one moment from the book—one sketch of Nancy Mairs' terrain—which they found memorable.

Small Group Discussion: Experiences with Disability (15 min.)

Separate into groups of 2 or 3. Allow each person about 5 minutes to share.

What images does disability bring to your mind? Have you or someone you love experienced disability or serious illness? If there have been people with disabilities in your family or community, what are (or were) your relationships with them? How have those relationships shaped your thinking about disability? How have your experiences with disability affected your reading of the book?

Large Group Sharing: Telling Body Stories (30 min.)

In the beginning of her book, Nancy Mairs talks about the particularity of her own body and her own disability. “My body. And only my body. The specificity of the personal pronoun is critical to me.” (p. 43) Each of our bodies has a unique history. Over the course of our lives, our bodies collect their own stories. Whether accidentally or intentionally, we mark our bodies and they, in turn, shape our lives.

Going around the group, ask participants to share a story about one of their body parts.

Share a short story of one part of your body—whether a wrist that pains you, a shoulder you chose to tattoo, a scar you bear, or a place where your body holds a memory.

Writing Exercise: Measuring Up (15 min.)

Our bodies often aren’t what we wish them to be. Nancy Mairs writes that, before she developed multiple sclerosis,

> mostly I was, as I was trained to be, disappointed in myself. Even in the fifties, before the dazzle of shopping malls and the soft pornography of advertising for every product from fragrance to bed linen, a girl learned to compare herself unfavorably to an ideal flashed at her on glossy magazine covers and cinema screens and then to take measures to rectify her all too glaring deficiencies. . . . I could not imagine a body that didn’t require at least minor structural modification.
> (p. 44)

Sometimes we shape what happens to our bodies, but often we have little or no control despite the myth that we can triumph over the body by willpower alone, or with the aid of make-up, muscle machines and other illusions.

Ask the group to spend about 10 minutes journaling. Tell people that they will be invited to share their entries with the group, but that they won’t be required to do so.

Write about a time when you felt your body didn’t measure up. Perhaps it didn’t do or look like what you or someone else wanted. Maybe you set a physical challenge that you couldn’t accomplish, or felt impeded by physical realities. How did you respond? Since that time, how have your feelings evolved?

After the writing, invite people to read a part of their writing aloud, if they wish. Remind the group that perfection isn’t necessary.

Group Discussion: Nancy's Story (30 min.)

In *Waist-High In the World,* Nancy Mairs invites readers into her own particular life. The details are uniquely hers, and she tells us that "At the outset, I want to make it clear that I speak as an individual and not as a representative of 'my kind,' whatever you take that to be." (p. 12) She also tells us that

> My hope is that, in scrutinizing some of these elements common to the human condition—among them adjustment to change, body image and sexuality, the need for both independence and nurturance, the ceaseless search for equality, justice, and pure pleasure—through the lens of my own experiences and those of people I know well, I can bring to life their particular significance in terms of disability. (pp. 11-12)

Her essays are decidedly personal, and yet they can resonate with our own needs, fears and hopes more broadly.

Have the group separate into groups of 2 or 3. Give each person about 5 minutes.

Where did you identify most with Mairs' story? What parts of her story were unexpected?

Return to the large group and share your reflections.

Nancy Mairs often speaks about nondisabled people's perceptions of her life. What struck you as most similar to your own perceptions? Most dissimilar? To what extent to you find your own life shaped and affected by other people's perceptions of your body or your self? How does the nondisabled world's power, privilege and perspective shape the lives of people who don't fit its definition of normalcy?

Reflection (10 min.)

Invite participants to reflect either through writing or through meditation, as they choose.

Recall a time when you experienced bodily change. What was difficult? How did the experience change your perspective or your thinking? What were the unexpected gifts?

Closing Reading

Thank the participants for their presence and participation. Close with reading #505 from the UUA Hymnal (Singing the Living Tradition) *or another reading of your own choosing.*

SESSION TWO

Materials: Newsprint, markers, masking tape, chalice, candle, matches, UUA Hymnal (*Singing the Living Tradition.* Boston: UUA, 1993), paper, pens

Opening Reading and Check-In (10 min.)

To open this session, light the chalice and share reading #562 from the UUA Hymnal (Singing the Living Tradition) *or another reading of your own choosing.*

After the reading, ask people to go around the circle and share briefly.

Have people check-in briefly and if they wish, invite them to share an instance in which they felt cared for since the last session.

Small Group Discussion: Giving and Receiving Care (30 min.)

Nancy Mairs talks about the tangible, physical ways we take care of someone as being good for the soul. She believes that "actively nurturing your fellow creatures through serving them… [develops] the part of the human psyche that transcends self-interest." She writes, "I want to *do* love." She acknowledges both the weariness and strain that caregiving brings her husband George, as well as the closeness and esteem that it brings.

Separate into groups of 3 or 4. Take about 5 minutes each to talk about giving care. Then take about 5 minutes each to talk about receiving care.

- ☐ What has your experience been with giving care? How have you felt its troubles and burdens? How have you experienced its benefits?
- ☐ What do we need from ourselves, our caregivers and our world to more authentically care for others and practice what Mairs' calls the nourishment of the soul?
- ☐ What makes it difficult to ask for care or accept help? What is at stake for us personally?
- ☐ What are the rewards of allowing ourselves to be helped? How can we become more gracious acceptors of other people's aid?

Large Group Discussion: Blending the Personal and Social Contexts (30 min.)

Our cultural myths and mores of independence are tied in with many beliefs about accepting care from others, and the social and political landscape often reinforces the idea that dependence is akin to worthlessness. Nancy Mairs writes:

> The dread of being a burden—physical, financial—on those one loves can only be inflamed by lawmakers with fat wallets and excellent health insurance who feel free to slash medical care for the elderly and people with disabilities in order to reward guess who? —people with fat wallets and excellent health insurance. . . . Such measures reflect the attitude that those of us who require care constitute an intolerable burden upon society, that we have nothing to offer to the human project, that we are, in fact, not worth taking care of. This implication breaks my heart. I am reduced to a vortex, sucking in the resources of all around me without replenishing them in kind. (p.76)

In the large group, discuss the following questions, encouraging people to draw upon their personal experiences.

- ☐ What social structures and cultural values make caregiving difficult? What social supports would increase our capacity to give and receive care?

- ☐ Where do we notice social messages that present people who are largely *taken care of* as burdens? In what ways do our personal actions contribute to this message? How could we (personally and societally) better value and appreciate their contributions?
- ☐ How can we better live out the Unitarian Universalist values of recognizing human interdependence and mutuality?

Journaling: Experiencing Loss (10 min.)

Nancy Mairs suggests that one reason nondisabled people avoid people with disabilities is to avoid also an encounter with their own limitations. She writes that

> the people who seem most hostile to my presence are those most fearful of my fate. And since their fear keeps them emotionally distant from me, they are the ones least likely to learn that my life isn't half so dismal as they assume. (p. 102)

The fear of loss haunts many of us.

Describing the emotional landscape of loss, Mairs writes that

> anguish is, after all, a predictable response to loss of any kind. What has surprised me, all the way along, is how little self-pity I've felt. . . . Here I was, after all: an attractive young woman of intellectual and artistic promise, with dependent children and a vigorous husband, cut down, platitudinously enough, in my prime. Here I am now, a quarter of a century later, prime well past, hunched and twisted and powerless but for two twelve-volt batteries beneath my ass. Woe is me! Except that, on the whole, woe *isn't* me. (p. 31)

Invite participants to journal about a loss that they experienced. Tell people that they won't be required to share their writing.

Write and reflect on a time when you experienced loss. Explore your own emotional landscape, both at the time and upon later reflection. What personal resources did you discover during the experience?

Small Group Discussion (15 min.)

After journaling, separate into small groups to share and discuss your reflections.

Invite people to read from their writing in small groups or share their thoughts. Groups might also discuss Nancy Mairs' reflection on her losses, and the different ways that people with different types of disabilities adapt to loss and change. (See pp. 28-29)

Large Group Conversation: When Woe Wasn't Us (15 min.)

While narrating the ways in which many people with disabilities respond to change and adapt to the physical circumstances with resourcefulness, Nancy Mairs writes that "what most people don't realize is that they would do it too."

In the large group, share reflections from small groups and other thoughts on:

- ☐ the ways of distancing from disabled people, in order to avoid an encounter with loss or risk, as Mairs says, "identification of their own lives with a life that dismays and perhaps even disgusts them."
- ☐ the capacity within us for finding resources to cope with difficulty, fear or loss; and
- ☐ our own "adventure stories" which remind us of the capacity to respond to change and difficult circumstances with ingenuity, resourcefulness and grace.

Preparing for the Next Session

Tell the group that one of next week's activities will involve discussing and critiquing common ways disability is represented in popular culture. Ask them to bring in some source material—advertisements, images, written descriptions or other places where people with disabilities appear. Medical advertisements, telethons, inspirational literature, and charities often provide prime source material for representing disability.

Closing Reading

Thank the participants for their presence and participation. Close with reading #696 from the UUA Hymnal (Singing the Living Tradition) *or another reading of your own choosing.*

SESSION THREE

Materials: Newsprint, markers, masking tape, chalice, candle, matches, UUA Hymnal (*Singing the Living Tradition.* Boston: UUA, 1993), paper, pens, photocopies of the Participant Evaluation Form

Opening Reading and Check-In (10 min.)

To open this session, light the chalice and share reading #463 from the UUA Hymnal (Singing the Living Tradition) *or another reading of your own choosing.*

After the reading, ask people to go around the circle and share briefly.

Large Group Exercise: Representing Disability (30 min.)

Share the popular representations of disability that the group gathered. Discuss and critique them according to Mairs' writing, looking for signs that emphasize or play on nondisabled people's pity, revulsion or fear. Where do the advertisements or stories indicate tragic tales, messages that this is a life not worth living, or inauthentic bravery and courage? Are there places were the representations suggest more authentic stories?

If you need more material, turn to the stories in Mairs' book. You might try John Hockenberry's airline story on p. 71, George's mother's desire to get away from the retirement home on p. 100, or the chapter, "Getting Byrned (pp. 146-169)."

This exercise can also be done in small groups, with groups coming back together to share their reflections with the large group.

Exercise: Social Construction of Disability (35min.)

The definitions of disability and impairment are shaped deeply by our social contexts and circumstances. Apart from the physical circumstances of our bodies, people often become more or less "disabled" based on the structures that support us—or fail to. Nancy Mairs writes that,

> The world as it is currently constructed does not especially want—and plainly does not need—me in it.… As a disabled woman, I find that my physical and social environments send the message that my presence is not unequivocally either welcome or vital. I am not looking for reassurances just now. I want to change the world. (pp. 87-88)

While we tend to think of disability as obvious and are less likely to question who belongs in the category of disabled, what constitutes a disability is actually profoundly affected by the built environment and our created cultural assumptions of normalcy.

Ask the group to consider the following statements. Read them slowly, allowing a pause for silent reflection after each.

Who would be disabled/handicapped if...

- ☐ if our lives required us to walk five miles every morning and evening for fresh water?
- ☐ if instead of a voice telephone, we communicated through silent images?
- ☐ if all doorways were three feet wide and three feet tall?
- ☐ if no furniture or chairs were provided in public spaces?
- ☐ if our safety depended on our ability to climb trees?
- ☐ if there were no lights or windows in public buildings?

Make up your own questions if you wish. Encourage the group to add questions of their own. After the exercise, turn to a neighbor and discuss:

- ☐ What was your reaction to the exercise?
- ☐ Which of these (or other) imagined social factors make you more or less disabled?

Return to the large group and discuss:

- ☐ What social factors pose the most trouble for Mairs, for you, or for people that you know who have disabilities?
- ☐ How is what we call "disability" affected by the world in which we live?

Group Conversation: A Life Worth Living

One of the privileges and powers of belonging to the nondisabled norm is the capacity to pass judgment on other people's lives, to decide that certain fates are obviously tragic and to en-deavor to spare people from their own suffering. Nancy Mairs observes the dangers in abortion to prevent children from being born with disabilities and the right-to-die movement, writing that

> the social construction of disability which makes me uneasy about urging abortion to prevent defective children disturbs me here, too. Behind the view of death as a right to be seized and defended lurks the hidden assumption that some lives are not worth living and that damaged creatures may be put out of their misery. (p. 120)

We are presented with many images of what makes life worthwhile—some that flow from our own hearts or spiritual sense, some that come from a culture that celebrates values we might not espouse.

Engage in a group brainstorm for about 10 minutes, asking for a volunteer to record responses on newsprint.

- ☐ What are we told makes "a worthy life?" What are the signs of a "life worth living?" From where do these messages come?

After the brainstorm, split into small groups for about 10 minutes.

- ☐ How do you react to these messages? What do you believe makes a life worth living?

Return to the large group and share responses.

If you wish, you may find it appropriate to discuss Nancy Mairs' concern for the respect of disabled peoples' lives and contributions. She writes,

> We can ill afford to kill off our geniuses, and every live birth holds such promise. [People with disabilities] will weave into the social fabric important strands of tenacity, patience, and ingenuity. We will all be glad they were born, I think. We will be glad they chose to live on. (p. 123)

Closing Circle: Choosing Joy

At the end of her book, Nancy Mairs writes of finding an old English castle largely inaccessible, and discovering only one room that she could reach. She says,

> I can huddle in it grieving over the rare and fabulous silver furniture the others will see upstairs in the King's Room without me. Or I can contemplate the ancestral portraits all around me, the elaborately ornamented oak screen at one end, and, when I've looked deeply enough, wheel out into the Green Court to bask in the rare bit of English sun, dreaming that Vita Sackville-West and Virginia Woolf once walked by this very spot, heads together, arms entwined, their laughter fluttering through the gate and out into the deer park beyond. Only one of these options will bring me joy. I choose joy.

In the closing circle, invite participants to share a time when they chose joy.

Closing Reading

Thank the participants for their reflection and for their sharing. Close with reading #507 from the UUA Hymnal (Singing the Living Tradition) *or another reading of your own choosing.*

Evaluations

Distribute the Participant Evaluation Forms. Ask participants to complete them and return them to you.

For further reading we recommend the following books by Nancy Mairs:
Carnal Acts: Essays (1996), *Remembering the Bone House: An Erotics of Place and Space* (1995), and *Voice Lessons: On Becoming a (Woman) Writer* (1994)

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Participant Evaluation Form

Name (optional): ______________________________ Date: ______________

Group Leader: ____

Book Title: ____

Please indicate your evaluation of the following:

meeting space	poor	fair	okay	good	great
pacing	poor	fair	okay	good	great
content	poor	fair	okay	good	great
overall	poor	fair	okay	good	great

1. Do you think the sessions were: (Please check one)

____too long ____about right ____too short

How long would you like the sessions to be? ______________________________

2. Do you think there were: (Please check one)

____too many sessions ____the right number of sessions ____too few sessions

If you thought there were too many sessions, which one(s) would you leave out?

____

3. If your large group broke into smaller groups for discussion, did this process work? Why or why not?

____

____

4. Is there anything that you would like to have talked about that was not included in the sessions? If so, what? ______________________________

____

5. What activity(ies) did you especially like? Why?______________________________

____

6. If there was an activity that you feel did not work in this context, can you tell us which activity and why? ______________________________

____

7. Question:

____

____

8. Question:

____

____

9. Please rate your group leader's skills in leading the session(s): (Circle one)

Excellent Good Average Fair Poor

10. What suggestions would you offer to the group leader to improve the way the group is conducted? ______________________________

____

Leader Evaluation Form

Name (optional): ________________________________ Date: ________________

UU Society: ______________________________________ District: ____________

Book Title: ____

1. Do you and/or your participants think the sessions were: (Please check one)

____too long ____about right ____too short

How long would you like the sessions to be? ______________________________

2. Do you think that there were: (Please check one)

____too many sessions ____the right number of sessions ____too few sessions

If you thought there were too many sessions, which ones would you leave out?

____

____

3. If your large group broke into smaller groups for discussion, did this process work?
Why or why not?

____

____

4. Is there anything that you would like to have talked about that was not included in the sessions? If so, what?

____

____

5. What activity(ies) did you especially like and why?

____

____

6. If there was an activity that you feel did not work in this context, can you tell us which activity and why?

____

____

7. Do you think the discussion guides will help to promote a stronger sense of community in your congregation? Why or why not?

____

____

8. Can you suggest other books or subjects that might work in this context?

____

____

9. If you changed the format, please describe the changes you made and your reason for making them.

____

____

Thank you for taking the time to give us your feedback!

Please return this form to:
Helene Atwan, Director
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Unitarian Universalism's Voice
for Good in the Twenty-First Century

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