Not Going Quietly
a film by Nicholas Bruckman

www.pbs.org/pov

POV Community Engagement & Education
DISCUSSION GUIDE
A rising star in progressive politics and a new father, Ady Barkan finds his life upended when he is diagnosed with ALS (amyotrophic lateral sclerosis). Then, after a chance encounter with a powerful senator on an airplane catapults him to fame, Ady and a motley crew of activists ignite a once-in-a-generation movement for universal health care, in a journey that transforms his belief in what is possible for the country and for his family.
This guide is an invitation to dialogue. It is based on a belief in the power of human connection and designed for people who want to use *Not Going Quietly* to engage family, friends, classmates, colleagues, and communities. In contrast to initiatives that foster debates in which participants try to convince others that they are right, this document envisions conversations undertaken in a spirit of openness in which people try to understand one another and expand their thinking by sharing viewpoints and listening actively.

The discussion prompts are intentionally crafted to help a wide range of audiences think more deeply about the issues in the film. Rather than attempting to address them all, choose one or two that best meet your needs and interests. And be sure to leave time to consider taking action. Planning next steps can help people leave the room feeling energized and optimistic, even in instances when conversations have been difficult.

For more detailed event planning and facilitation tips, visit [https://communitynetwork.amdoc.org/](https://communitynetwork.amdoc.org/).
KEY PARTICIPANTS

**ADY BARKAN** - The central focus of the film. A fierce advocate for healthcare services for all/Medicare for all, Ady was diagnosed with ALS at age 32

**RACHAEL KING** - Associate professor of English at University of California, Santa Barbara. She is Ady’s wife and mother of their children, Carl and Willow

**LIZ JAFF** - Political activist and organizer. Her chance encounter with Ady in an airport led to the creation of the Be a Hero campaign, and the cross-country tour chronicled in the film

**NATE SMITH** - Ady’s best friend, companion, caregiver, and driver for the cross-country tour

**TRACEY CORDER** - Teaches people how to utilize bird-dogging when approaching elected officials and candidates

**ANA MARIA ARCHILA** - A leading activist locally and nationally whose encounter with Senator Flake in an elevator goes viral

**NICHOLAS BRUCKMAN** - Director and writer and the founder/director/EP of People’s Television

**AMANDA RODDY** - Producer and writer and documentary filmmaker with People’s Television

KEY ISSUES

*Not Going Quietly* is an excellent tool for outreach and will be of special interest to people who want to explore the following topics:

- People-power and civic responsibility
- Grassroots organizing
- Bird-dogging as a method to engage your elected officials
- Health care and systemic inequity
- Medicare for all
- Healthcare delivery in the United States
- Amyotrophic lateral sclerosis (ALS)
- The negative impact the tax cuts for the richest Americans have on millions of low-income and working-class Americans.
- Sacrifices involved in activists’ lives
- Intersection of justice-oriented movements
- Social media and social change
Who Is Ady Barkan?

In 2019, Ady Barkan was profiled in the *New York Times* and *Politico Magazine*, and in 2020 he was on Time’s 100 Most Influential People List. Each profile described him as one of the most powerful advocates in the country. Born and raised in California, Ady went on to attend Columbia University and Yale Law School. Following law school, he clerked for a federal judge in New York City. Always driven by a commitment to social justice, he was inspired by the *Occupy Wall Street movement* to work to create more equitable conditions for everyday people and dedicate his life to working for change on behalf of people who are not traditionally heard.

Following his clerkship, he went on to work for the *Center for Popular Democracy*, an organization based in Brooklyn that bolsters collective capacity through organizing on behalf of workers and immigrants and toward racial and economic justice. While there, he was managing campaigns throughout the city and across the country, and his reputation as a successful organizer began spreading within activist communities. Ady married Rachael King, who he had met at Columbia. Rachael is a tenured associate professor at the University of California, Santa Barbara. They have two young children, Carl and Willow.

Amyotrophic Lateral Sclerosis (ALS)

The *National Institute of Neurological Disorders and Stroke* defines amyotrophic lateral sclerosis (ALS) as “a rare neurological disease that primarily affects the nerve cells (neurons) responsible for controlling voluntary muscle movement (those muscles we choose to move).” Voluntary muscles are those that make everyday movements like talking, walking, and chewing possible. ALS is a progressive disease, which means the symptoms worsen over time. Currently, there is no cure or effective treatment to reverse or stop the progression of the disease.

ALS is caused by gradual deterioration of motor neurons, which extend from the brain to the spinal cord and, through muscles, throughout the body. As the disease progresses, muscle weakness and atrophy. The impact of ALS and its rate of progression vary from person to person; however, those who live with ALS will all eventually lose their motor skills. Importantly, as the *National Institute of Neurological Disorders and Strokes* notes and as we see in the film, “ALS does not impair a person’s intellectual reasoning, vision, hearing, or sense of taste, smell, and touch.”

According to Johns Hopkins Medicine, ALS affects as many as 30,000 people in the United States, with 5,000 new cases diagnosed each year, and is responsible for approximately
fifty out of every 100,000 deaths in people aged 20 or older. While most develop ALS between the ages of 40 and 70, it is most common among people over the age of 60. Growing research and improvement in medical management of the disease make it possible for people with ALS to continue living productive lives. Johns Hopkins Medicine states, “Fifty percent of affected patients live at least three or more years after diagnosis; 20 percent live five years or more; and up to 10 percent will survive more than ten years.”

Many people refer to ALS as “Lou Gehrig’s Disease.” Lou Gehrig was one of the most successful players in major league baseball until, at the age of 36, he was forced to retire after he developed a neurological disorder that was later identified as ALS. He is well known for his final speech at Yankee Stadium where, upon saying, “Today, I consider myself the luckiest man on the face of this Earth,” he received a standing ovation. Gehrig died two years after receiving his diagnosis.

**Ady’s Diagnosis and Commitment to Medicare for All**

Ady Barkan began experiencing some weakness in one arm soon after the birth of his son, Carl. After a number of tests and consultations, at age 32, he was diagnosed with ALS. Though he and Rachael had health insurance through Rachael’s employer, like so many other Americans, they faced a lack of coverage. After learning that their insurance company would not pay for a breathing machine that Ady’s physician had ordered and that Ady needed to live, Ady—with Rachael’s involvement and support—made the decision to direct his organizing skills toward fighting for healthcare reform so that he, and millions of other Americans, could receive the support they deserved.

As we see in the film, Ady and his team organized to demand action in support of Medicare for all. Medicare for all, commonly referred to as universal healthcare, refers to a healthcare system where every individual has health coverage. In Canada, for example, the government-run universal healthcare system means that there are no uninsured Canadian citizens. (However, as we continue working to understand the dynamic intersections of justice-oriented movements, it is important to remember that undocumented citizens do not receive the benefits of universal health care.) Single-payer healthcare is one such approach, where the government uses tax systems to cover the cost of healthcare claims. In the United States, Medicare is a single-payer program. Under Medicare, the U.S. government (as a single payer) provides health care for people over the age of 65. Another example of a single-payer system in the United States is the Veterans Administration (VA), but the VA enhances social support for healthcare in that the U.S. government additionally employs medical staff and operates hospitals for U.S. veterans. Effectively, proponents of universal healthcare—like Ady—believe that all people should have access to consistent and trusted health services as a public service provided by the government.
Health care in the United States is a political issue due to the private health insurance model and, as we see in _Not Going Quietly_, candidates for office often resist transparency with regard to their stances on universal healthcare models. Fighting for transparency, Ady challenged Democratic presidential candidates to go on record stating their positions on Medicare for all and healthcare reform. He traveled to congressional districts across the country and organized rallies of constituents who targeted members of the House of Representatives who were not supporting healthcare reform. Ady has not stopped and will never stop advocating for himself and other Americans. Though he is now supported by a respirator to aid his breathing and a technology called Eyegaze, which has laser beams that track his eyes following lines on a screen and converts that into machine recordings that then use his voice to communicate with others, he continues to engage in the collective struggle for healthcare reform.

**People, Politics, and the Be a Hero Campaign**

In 2010, the Obama administration passed the Patient Protection and Affordable Care Act (ACA), which made it possible for millions of previously uninsured Americans to attain health insurance. During the Trump administration, plans to repeal and replace the ACA were a major talking point for politicians who opposed the legislation, and though repealing and replacing never materialized, tax cuts for the nation’s wealthiest people and corporations passed in 2016 negatively impacted the lives of Americans who depend on Social Security, Medicare, and Medicaid. These tax cuts increased the national debt by 2.3 trillion dollars and were accompanied by budget reductions that cut benefits to the nation’s most vulnerable populations—the elderly, people with disabilities, and children. Individual mandate penalties were also put into place and resulted in more than 10 million people losing affordable qualified health coverage; millions of family members who are caregivers were significantly impacted. These political decisions, made by those who hold power, impact everyday people in life-changing ways across the country.

The Be a Hero campaign began after a video of Ady confronting Senator Jeff Flake of Arizona went viral and mobilized activists in congressional districts across the country to fight for healthcare justice. Rachael and Ady agreed that organizing events across the country through the Be a Hero campaign was necessary, even though it meant sacrificing family time. Along with Liz Jaff, Nate Smith, Tracey Corder, and others, Ady embarked on a cross-country road trip rallying advocates and pressuring members of Congress to challenge the Trump tax cuts for the richest Americans.

It was during this period that Ady returned to Washington to oppose the nomination of Brett Kavanaugh to the Supreme Court following the sexual misconduct accusations brought against the nominee by Christine Blasey Ford.
Joining advocates, including Ana Maria Archila, Ady again returned to the U.S. Capitol. They found themselves outside the offices of Senator Flake. Ady took a step back and created the space for Ana Maria to share her own experiences with sexual abuse and to directly confront Senator Flake as he tried to rush into an elevator to cast his vote on the nomination.

Ady's efforts made a profound difference and have been credited in part for returning the House of Representatives to Democratic control. Using this increasing recognition, Ady was able to engage every candidate in the 2020 Democratic presidential campaign, challenging them to articulate what they would do regarding health care if they received the nomination. This act of courage elevated the issue of health care as a right for all Americans and the importance of Medicare for all.

In April 2019, Ady testified before the House Committee on Rules in favor of Medicare for all at the first-ever congressional hearing on the subject. On the second day of the 2020 Democratic National Convention, Ady spoke about the importance of health care for all and his support of the Biden/Harris ticket. The Be a Hero campaign and PAC remain powerful forces today in the fight for Medicare for all and social justice. A focus today is to include funding for homecare services in President Biden's Build Back Better bill. This film offers a glimpse of Ady Barkan’s life, the strength, love, and commitment of his wife, Rachael King, and the true impact of the U.S. healthcare system on millions of people.

Bird-dogging and the Importance of Organizing for Collective Action

Bird-dogging is a grassroots political strategy implemented by activists and citizens to get elected officials and candidates to speak on the record—and off the cuff—about consequential issues. As an intervention, bird-dogging puts politicians in the hot seat and doesn’t let up. As seen in the film, training and strategic planning ahead of time ensure that this strategy will be successful. It requires, at minimum, two people who have decided on a question of importance beforehand and then strategize when and how the question will be asked in such a way that conditions are created so that the politician has no other choice but to respond.

One possibility is an informal, unscripted scenario where one person shakes the representative’s hand while a teammate is recording the exchange. The point at which participants are face-to-face, or hand-in-hand, with the representative is when the question is asked audibly and clearly. Bird-dogging requires anticipating the representative’s attempt to sidestep responding, so activists are trained to continue pushing with the question in order to intervene in an official’s attempt at deflecting or avoiding direct response. As these encounters are recorded, the exchanges are often published on social media, leveraging
the unique ways social media can and has changed the landscape of grassroots activism.

Ultimately, bird-dogging is an insistence that people have power and an opportunity for people to take their power back in collective spaces and to demand accountability from representatives and officials. You can learn more about bird-dogging and ways to engage here.

**Sources**


DISCUSSION QUESTIONS

1. What is your initial reaction to the film? What feelings come up for you? How do you feel in your body watching this film?

2. If you could ask Ady one question or say one thing to him, what would it be?

3. What in the film surprised you the most? What aspects of the film inspired you the most?

STARTING THE CONVERSATION

Immediately after the film, you may want to give people a few quiet moments to reflect on what they have seen. You could pose a general question (examples below) and give people some time to themselves to jot down or think about their answers before opening the discussion. Alternatively, you could ask participants to share their thoughts with a partner before starting a group discussion.

- What is your initial reaction to the film? What feelings come up for you? How do you feel in your body watching this film?
- If you could ask Ady one question or say one thing to him, what would it be?
- What in the film surprised you the most? What aspects of the film inspired you the most?
RESPONSIBILITY FOR ALL: LEARNING FROM ADY BARKAN

- What does Ady’s commitment to political change after receiving his diagnosis of a terminal illness teach us about the possibilities for personal experiences to inform political will? Name some reasons it is important for individuals to fight for equality, in a democratic country, when they haven’t been personally impacted or harmed by systemic oppression.

- In what ways does this film authentically represent the realities of both struggle and resilience without glorifying either?

- Ady’s diagnosis of ALS comes with a predictable outcome, and viewers are allowed an intimate glimpse into how he and his family negotiate a future that is beyond their control. While political decisions might sometimes feel beyond everyday citizens’ control, in what ways does Ady’s commitment to activism after his diagnosis invite you to think differently about agency, change, and possibility?

- One of Ady’s motivations in allowing the filmmakers such intimate access to his life was to leave something for Carl and Willow. How do the legacies we wish to leave behind for those we are closest to also impact a larger community?

- What lessons does Ady’s commitment to activism, alongside his commitment to being a good parent and husband, offer about the importance of feeling accountable to future generations?
  - In what ways are the futures of our own family members and children interconnected with the futures of other families and children?

- In *Not Going Quietly* there is a balance between footage of Ady at home with his family and Ady on the road. In what ways are love, care, and intimacy reflected in both settings? What did this teach you about possibilities for community and care in politics and activism?
  - What does this film teach us about the importance of allowing others to support us?

DISABILITY, ACCESSIBILITY, AND SACRIFICE

- In what ways did *Not Going Quietly* impact how you think about accessibility, activism, and your own civic engagement?

- What barriers, if any, have kept you from feeling that political and civic engagement are places where you can be an active participant? In what ways does this film make
you reconsider how you’ve viewed those barriers or inspire you to approach activism differently?

• What lessons can activists learn from this film with regard to making grassroots communities collectively accessible so that differently-abled people are supported structurally and individually in political participation?

• In what ways are acknowledging and honoring differences crucial components of justice-oriented futures?

• Though the backdrop of the film is Ady’s ALS diagnosis, *Not Going Quietly* also focuses on Ady as a father, a husband, a friend, and an activist. How does it do so? In what ways does this film invite you to reflect on how people with disabilities are treated in everyday life and represented in media?

• In what ways has this film invited you to think critically with regard to how you are treated as a person with disabilities and/or how you treat differently-abled people in your life and community?

• Though this film centers Ady as an activist for healthcare reform, what are some examples of how community was essential to Ady’s continued involvement in politics? What does this teach us about the crucial need for community, trust, and support in our everyday lives?

• Many people in the film make sacrifices for causes greater than themselves. Who are some subjects who made personal sacrifices for the sake of the public good? What does this film teach us about those behind the scenes and their crucial roles in making possibilities for political change more realizable?

• What are some examples of barriers to accessing healthcare in the U.S.?

• In what ways are these barriers less important than human beings receiving the life-saving care they might require?

• Ady claims that dealing with insurance companies is even worse than knowing he is dying. In what ways does the current healthcare system in the U.S. cause suffering rather than offer support to those who most need it?
GRIEF, LOSS, AND POLITICS

• In what ways might our political commitments to change be impacted if we took seriously our limited time, our mortality, and the legacies we aim to leave behind? What does Ady’s story invite you to consider with regard to the certainty of death?

• Though many consider grief something that happens after death, anticipatory grief is an experience people can have before death or dying. This type of grief emerges in preparation for losing a loved one; or, for those who are dying, in response to loss of independence or abilities. In what ways did you witness grief emerging in this film?

• What, if anything, was compelling or unsettling about the honesty with which death and grief were discussed in this film? Why?

• If death and grief are common experiences, why might we tend to avoid conversations that directly address death and loss? How might our approaches to caring for one another and ourselves be changed, or benefit, from more candid conversations about the ways death and loss have changed us?

• In what ways might loss and grief be made into a resource for political communities?

• In what ways does death impact structural support (i.e., housing, economic security, care, guardianship) for those who experience loss? How is thinking about death and loss a political and structural concern for those who desire equity?

• In what ways might universal healthcare support conditions that would ensure every living person has the opportunity to die with care, support, and dignity?

ADVOCACY LESSONS: SOCIAL MEDIA AND SOCIAL CHANGE

• In what ways did Not Going Quietly highlight the power of everyday people to participate in politics and to document political encounters?

• How did social media function as an important tool in activists’ strategies? What are some ways social media can be leveraged in changing political landscapes to support grassroots movements?

• In what ways does posting political encounters on social media (as we witness in the bird-dogging training scene) impact issues of accessibility?
• In what ways did activists in the film engage in joy and community-building throughout their tireless work? What did this teach you about the importance of joy and community in political organizing?

• A very powerful scene in the film is when Ady steps back so Ana Maria Archila can share her experience as a survivor of sexual assault during the Brett Kavanaugh nomination. In what ways do political events, like the nomination of Kavanaugh, often exclude the stories and experiences of everyday people?

• In what ways does Ady prioritizing Ana Maria's testimony highlight dynamic intersections of power, privilege, and identity to offer models for activists engaged in different, though interconnected, struggles for justice?

• What are some (potentially new) ways Not Going Quietly expanded your understanding of what activism can look like and/or inspired you to get involved in local or national politics?

**CLOSING QUESTION/ACTIVITY**

• At the end of your discussion, to help people synthesize what they’ve experienced and move the focus from dialogue to action steps, you may want to choose one of these questions:

• After seeing Ady refuse to be sidelined, what are things that you have allowed to hold you back that you now recognize you can move beyond?

• Relationships are important. We can see the unconditional love between Rachael and Ady and Ady and Nate, as well as the powerful bond between Ady and Liz, and, of course, Ady’s love of Carl and Willow. Think about the people in your life and consider whether you have told them what they mean to you and their importance in doing the work that you do.
  • Consider, also, the role of relationships in forming bonds within activist communities and political spaces. What role does trust play in cultivating and sustaining social movements?
TAKING ACTION
Here are ways you and your community can get involved and address the issues illuminated in Not Going Quietly.

• Host a screening of Not Going Quietly in your community through the POV Community Network.

• Identify your elected officials and representatives here.

• Research the positions that your elected officials and candidates have taken on the things that matter to you. If they do not reflect your views, consider attending one of the official’s public forums or make an appointment to visit their office. Be prepared to tell them what you want to see them do and why this is a critical issue.

• Join a local advocacy/nonprofit and become more active in working for meaningful change.

• Submit an op-ed to your local newspaper sharing your story and what needs to change.

RESOURCES

Not Going Quietly - The film’s website includes resources for taking action and opportunities to donate.film page

HEALTH CARE IN THE UNITED STATES


Be a Hero - Be a Hero PAC is a national progressive organization that works tirelessly to advocate for a more fair and just healthcare system in the United States. Founded by ALS activist Ady Barkan and Liz Jaff in 2018, Be a Hero has grown rapidly and helped shape the dialogue on healthcare advocacy and accountability in America. https://beaherofund.com/


Kaiser Family Fund: “Understanding Health Insurance” - This FAQ covers all aspects of the current U.S. healthcare scenario. https://www.kff.org/understanding-health-insurance
**DISCUSSION QUESTIONS**

**National Committee to Preserve Social Security and Medicare** - This organization works to protect, preserve, promote, and ensure the financial security, health, and wellbeing of maturing Americans. [https://www.ncpssm.org/our-issues/medicare/](https://www.ncpssm.org/our-issues/medicare/)


**ALS**

**The ALS Therapy Development Institute** - The ALS Therapy Development Institute is the world’s foremost drug discovery lab focused solely on ALS. A nonprofit biotech led by drug development experts and people with ALS, the Watertown, Massachusetts–based lab is funded by a global network of supporters unified to end ALS. Its mission is to discover and develop effective treatments for ALS. [https://www.als.net/](https://www.als.net/)

**I AM ALS** - I AM ALS is a patient-led community that provides critical support and resources to patients, caregivers, and loved ones. It empowers advocates to raise mainstream awareness and lead the revolution against ALS in driving the development of cures. [https://iamals.org](https://iamals.org)


**BIRD-DOGGING**

**HEALTHCARE-NOW** - This organization explores bird-dogging in relation to seeking Medicare for all. [https://www.healthcare-now.org/complete-guide-to-birddogging/](https://www.healthcare-now.org/complete-guide-to-birddogging/)

**MoveOn** - MoveOn offers a primer on bird-dogging. [https://front.moveon.org/how-to-birddog/](https://front.moveon.org/how-to-birddog/)

**Move to Amend** - Move to Amend offers tips for bird-dogging both candidates and elected officials. [https://www.movetoamend.org/tips-bird-dogging-candidates-elected-officials](https://www.movetoamend.org/tips-bird-dogging-candidates-elected-officials)

**Open Democracy Action** - An organization that works to get big money out of politics explains bird-dogging. [https://www.opendemocracyaction.org/birddogging](https://www.opendemocracyaction.org/birddogging)

**YouTube: “Bird Dogging Elected Officials”** - Hugh Espey of Iowa Citizens for Community Improvement covers four aspects of bird-dogging. [https://youtu.be/g6oI8I8fsc](https://youtu.be/g6oI8I8fsc)


**MEDICARE FOR ALL AND THE BRETT KAVANAUGH NOMINATION**


**DISCUSSION GUIDE**

**Not Going Quietly**

ADY BARKAN


DR. CHARLES ROBBINS

Charles L. Robbins is a professor in the School of Social Welfare, Affiliated Faculty in the Program in Public Health and Executive Director of the Center for Changing Systems of Power at Stony Brook University in New York. Previously he served as the vice provost for undergraduate education and student success at Stony Brook University. Dr. Robbins received his BS degree from the State University of New York at Cortland; an MSW from Adelphi University; and a DSW from the Wurzweiler School of Social Work at Yeshiva University.

The focus of Dr. Robbins’s scholarship and work is on social justice, gender equality, masculinities, the LGBTQA+ community, and healthcare disparities. He is a frequent speaker at local, national and international conferences. In addition to North America, he has worked in Africa, Australia, South America, Asia, and Europe. Dr. Robbins consults with universities, not-for-profit organizations, and corporations around gender and diversity, equity, and inclusion.

Dr. Robbins is a member of the global board of MCW Global, whose mission is to address communities’ pressing needs by empowering current leaders and readying the leaders of tomorrow. His primary focus has been on working with emerging young leaders. Dr. Robbins has been an official NGO delegate to the United Nations.

Discussion Guide Producer, POV
Courtney B. Cook, PhD | Education Manager

Thanks to all who reviewed this guide:
Nicholas Bruckman | Director, Not Going Quietly
Aster Gross | Associate Producer, Not Going Quietly
Ady Barkan | Co-Founder, Be A Hero, and Activist