Telling Patient Stories

Framing Effective Communications for Advocacy
The Power and Paradox of Patient Stories
Patient stories can:

- Provide a human face to your narrative
- Attract the interest of journalists and the public
- Make people relate to the issues you care about
- Bolster fundraising
- Reduce stigma
- Demonstrate your impact on people’s lives
- Draw unwarranted judgements
- Increase stigma
- Create an unrealistic understanding of the problem
- Alienate your audience
- Overwhelm your audience
- Reinforce negative false opinions
Framing Matters

Focus on your client / patient

How has this issue impacted other aspects of their life?

- Finances
- Social relationships
- Economic opportunity

Focus on the structural barriers facing your client

What are the barriers that individuals can influence or control? Who is the villain in creating these barriers?

- Lack of funding for community health centers
- Discriminatory practices committed by landlords, potential employers, etc
- Stigma perpetuated by community members or peers
Dangers in Crafting Stories About Marginalized Groups

**Boomerang Effect**: An attempt to convince someone to adopt an opinion results in them adopting the opposite position.

**Confirmation Bias**: The tendency to interpret new evidence as confirmation of one's existing beliefs or theories.
Drinking too much can have many risks for women.

For any pregnant woman and baby:
- miscarriage
- stillbirth
- preterm delivery
- fetal alcohol spectrum disorders (FASDs)
- sudden infant death syndrome (SIDS)

For any woman:
- injuries/violence
- heart disease
- cancer
- sexually transmitted diseases
- fertility problems
- unintended pregnancy

Drinking too much for women includes:
- any alcohol use by women who are pregnant or might be pregnant.
- 8 or more drinks per week (more than 1 drink on average per day)
- binge drinking (5 or more drinks within 2-3 hours)
- any alcohol use by those under age 21

Doctors, nurses, or other health professionals should screen every adult patient, including pregnant women, and counsel those who drink too much. Providers can help women avoid drinking too much, including avoiding alcohol during pregnancy, in 5 steps.

1. Assess a woman’s drinking:
   - Use a validated screener (e.g., AUDIT-C/LSR).
   - Take 6-15 minutes to explain results and provide counseling to women who are drinking too much.
   - Advise her not to drink at all if she is pregnant or might be pregnant.
   - Come up with a plan together.

2. Recommend birth control if a woman is having sex (if appropriate), not planning to get pregnant, and is drinking alcohol:
   - Review risk for pregnancy and importance of birth control use.
   - Discuss full range of methods available.
   - Encourage her to always use condoms to reduce risk of sexually transmitted diseases.

3. Advise a woman to stop drinking if she is trying to get pregnant or not using birth control with sex:
   - Discuss the reasons to stop alcohol use before the woman realizes she is pregnant.

4. Refer for additional services if a woman cannot stop drinking on her own:
   - Provide information on local programs or go to SAMHSA treatment locator:
     www.nhs治ment.samhsa.gov
   - Consider referral to treatment or recommend Alcoholics Anonymous:
     www.aa.org

5. Follow up yearly or more often, as needed:
   - Set a time for return appointment.
   - Continue support at follow-up.


Season 2
Price Of A Brace Brings Soccer Player To His Knees

Meow-ch! The $48,512 Cat Bite
The hospital billed her close to $50,000 for a treatment that typically costs about $3,000.

Hope You’re Sitting Down
He fainted after getting a flu shot. The trip to the ER cost him his whole deductible.

An Uphill Battle
When her metal plate failed, she and her insurer had to pay full price for its replacement.

Kaiser Health News “What The Health” series
Telling Stories to Affect Change

Problems may seem overwhelming, but don’t overwhelm your audience.

Always have a call to action and an opportunity for the reader to act.

Meet your audience where they are.

Remember to talk about your organization’s impact.
Selecting Stories

Your patient may be the “face” of this story, but they must be relatable.

Vet these stories and patients first.

Prepare your patient for the next steps:

- Ask if they are comfortable sharing their story to bring attention to the issue.
- Let them know that they can speak on or off the record, and can use only their first name, a pseudonym, or be anonymous.
- Be clear about what health information can or cannot be shared.
- Make the initial contact through your organization, do not give a patient’s information directly to a journalist.
Telling Your Stories Through Media

Media can help:

- Fundraising
- Speaking to your members
- Motivating grassroots activity
- Informing your followers of the issues
- Connecting you with those who can help
- Creating real change
### Social media
- Create your own content, for free.
- Reliance on others to amplify your message.
- Need to break through the noise.

### Earned media
- Gives credibility to your issue or cause.
- Higher chances of getting your story in front of the right people.
- Takes time to develop a story with a journalist.
- Coverage relies on a tie to something newsworthy or a new development.

### Organization media
- Ability to write your own story.
- Distribution can be challenging.
- Trust in your organization is key to a reader.
- Content creation is time consuming.
Social media

Think visual! A picture tells a thousand words.

Twitter, Facebook, Instagram, Snapchat, LinkedIn all attract different demographics. Know your audience!

Social media is a conversation - speak with your followers the way you would a friend.

Images and videos showing positive human connection boost engagement.
Social Media Can Inform You!

**Twitter accounts:**
- Sec. Alex Azar: @SecAzar
- HRSA: @HRSAgov
- Adm. Brett Giroir: @HHS_ASH
- Dr. Robert Redfield: @CDCDirector
- HIV.gov: @HIVgov
- NIH: @NIAIDnews
- CDC HIV/AIDS: @CDC_HIVAIDS
- NIH AIDS Info: @AIDSinfo

**Hashtags:**
- #EndHIVEpidemic
- #EtE
- #EndHIV

**Organizations:**
- NASTAD: @NASTAD
- AIDS United: @AIDS_United
- NMAC: @NMACCommunity
- TargetHIV: @ryanwhitecare
Earned media

National news, local broadcast news outlets, national syndication news outlets, niche trade press, radio, podcasts, and more.

Research the right outlet and the right journalist to tell your story.

Patient’s perspective / experience is key!

Tell the patient’s whole story, with an eye on cracks in the system.

Be prepared to follow up!
Organization Generated Media


Have a clear message on the problem, and use your stories as an example.

There may be numerous issues, but focus in on one main point.

You control your own distribution.

Headlines matter!
Thank you!