

3 Story Texts & 3 Story Images

Part A. Data “Top 10 Relevant Facts”

List 10 short factual pieces of information that are central to your “care” story. (In other words, your story - related to providing and/or receiving care or LTSS support.) Think of specific information that distinguishes you and your situation. (ie Age, Housing Status, Migration Status, Job/Career, Income, Costs of Services, Diagnosis/Symptoms/Treatments).

1	<i>My name is Felicia T Perez</i>
2	<i>I am from Orange, California and currently live in Reno, Nevada</i>
3	<i>JRA (age 4), Asthma (age 25), PCOS (age 30), Eye/Brain Tumor (age 36), Pernicious Anemia (age 37), Menopause (age 38), Cataracts (age 41), Detached Retinas (age 44)</i>
4	<i>There was a time before when my health was better and not as costly</i>
5	<i>December 18, 2012 I learned I either had a rare eye cancer or a rare autoimmune disorder that will lead to lymphoma</i>
6	<i># of MRIs, IVIG, Radiation Treatments, Chemo Infusions, Daily Pills, B-12 Injections</i>
7	<i>The Affordable Care Act allows me to access these life saving medications through my spouse’s employment insurance</i>
8	<i>I need chemo for the rest of my life and each treatment costs \$20,000</i>
9	<i>I was not prepared for the costs of my health care, even with health insurance (\$7,800 a year out of pocket max)</i>
10	<i>I used to be a high school history teacher in Los Angeles (LAUSD) for 12 years before the tumors began and now I am a college lecturer at the University of Nevada Reno</i>

Any Other Relevant Information? Note it below.

- *Spouse/Partner is my primary caregiver, Emily Hobson*
- *Depending on the treatment and my current health at the time, I have worked part time and full time. My chemo medication costs different amounts per state and per country (US \$20K, CAN \$15)*
- *I have lost part of my vision*
- *I use a cane 80% of the time*
- *My parents are of Mexican Descent. My father immigrated to the US in 1965*
- *I identify as queer*
- *I create/have a lot of medical waste*
- *Movement ancestors I admire and owe: Chadwick Boseman, Ryan White, Fannie Lou Hamer, Vito Russo, Silvia Rivera.*
- *Key Framing: “Live and age with dignity” #ACAforLife #LiveAgeWithDignity*

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Part B. Characters and Imagery

Think about the way you usually explain your situation to someone. Or practice telling your story to someone now. List out the following details of the story you tell.

Character Description <i>Name? What do they look like? What do they sound like? How does it feel?</i> (*Can be a person, place, or thing/item)	How are they cast or portrayed? <i>Victim, Villain, Hero</i> (*Can be more than one)
<i>Me, Felicia T Perez - bald, uses cane, with glasses, one slightly droopy eye, tired, sad (crying), angry, scared, determined, illness invisible</i>	<i>Victim & Hero</i>
<i>My partner/caregiver - tired, sad, angry, scared, determined, invisible, often unsupported</i>	<i>Victim</i>
<i>Planking - outside, still, unique, living</i>	<i>Hero</i>
<i>The chemo chair - inside, stiff, the same, surviving, dying, constant beeping, bell ringing</i>	<i>Villain & Hero</i>
<i>The medicine - vessels, bottles, syringes, helps & harms, familiar sound like candy/pennies/pills</i>	<i>Villain & Hero</i>
<i>Money - a lot of it, going to unintended purpose, not having enough, precarious</i>	<i>Victim, Villain & Hero</i>
<i>The Affordable Care Act - not enough, without it access to life saving medications is precarious or absent</i>	<i>Victim, Villain & Hero</i>
<i>People in Positions in Power who are trying to dismantle the ACA and access to health care (state & federal representatives, judges, etc)</i>	<i>Villain</i>

Any Other Relevant Characters?	Historic or Current Characters?
<ul style="list-style-type: none"> <i>Medical professionals</i> <i>Government Representatives</i> <i>Quality of Life</i> <i>Affordable Care Act (ACA)</i> 	<ul style="list-style-type: none"> <i>AIDS Activists / Access to Medicine</i> <ul style="list-style-type: none"> <i>Ryan White & Vitto Russo</i> <i>Power Storyteller Advocates</i> <ul style="list-style-type: none"> <i>Fannie Lou Hamer & Sylvia Rivera</i>

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Part C. FairyTale

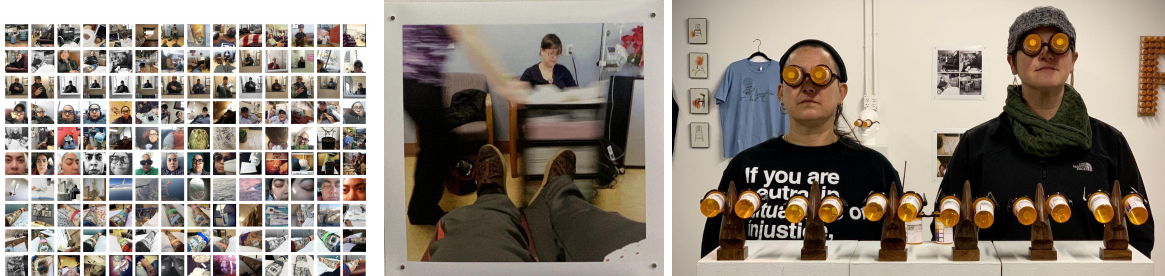
Imagine you are trying to explain your story as if it was a fairytale.

Element of the Fairy Tale	Guiding Question	What this Does
1. Context <i>Once upon a time...</i>	What does your audience need to know to understand this story?	Explains your relatable character
<i>In August of 2012 I had just completed my 12th, and final year, as a high school history teacher in the city of Los Angeles in California. I was on my way to start a new life with my partner, as we were now moving to Reno Nevada where they had just gotten their first job teaching history at the local university.</i>		
2. An inciting moment/Pivot <i>Then one day...</i>	What has changed?	Introduces your obstacle
<i>After living in a new town for only one month I began to have unexplainable health issues related to my eye. Every morning I would wake to find that my right eyelid was completely swollen shut. Initially I was given eye drop after eye drop with no change at all. And then everything did change when my doctor said I needed an MRI to rule out a brain tumor. My 1st MRI revealed that I had a large tumor wrapped around my eye and brain. I would need a biopsy to finally determine if I either had a rare eye cancer, with up to 5 years to live, or a rare autoimmune disorder that will keep creating tumors eventually leading to a form of lymphoma.</i>		
3. Heightening <i>And because of that...</i>	How are stakes growing?	This is why we care about the character and the goal
<i>After several experimental medications and 11 rounds of radiation, I now need 8 chemo infusions a year and monthly B-12 injections in order to stay alive. Accessing that medical care is only available to me with the existence of the Affordable Care Act and my current ability to pay \$7,800 a year to pay for my insurance's "out of pocket max" costs. My caregiver, like me, is growing tired of the stress of it all. I only have the healthcare that I need because of their job. If they lose their job or change jobs everything about my life changes too.</i>		
4. Revelation <i>Until finally...</i>	How do things get better?	Explains how the obstacle is overcome
<i>If we had universal health care everything would change for the better. If the Affordable Care Act was expanded and not under attack constantly my mental health in particular would be better. If health care was not attached to your job or family that would mean more autonomy and access.</i>		
5. Resolution <i>And ever since...</i>	What does the future look like because of this story?	This is the admirable, obtainable goal
<i>I am no longer afraid of the mail and the bills that may be there waiting for me. I live in a world free of GoFundMe campaigns to help pay for health care that should be free. I have a quality life where I don't see my body as the villain in my own story. I feel happy, joyous and free.</i>		

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Part D. 3 Story Texts & 3 Story Images

This is the final step. Take a moment to review all that you have put together in the earlier sections of this worksheet and use them to create 3 slightly different compelling stories with 3 different images. Remember, that each text/image will be different depending on its intention (**Organizing**-build relationships, **Advocacy**-influence, **Mobilizing**-motivate).

Intention	Text
<p>Organizing Stories that connect individuals & build relationships (Part C. 1-3)</p> <p>Sympathy, Empathy, Admiration</p>	<p>On December 18, 2012, I was 36 years old and sitting in a doctor's office learning that either I had a rare eye cancer with up to 5 years left to live, or an equally rare and incurable autoimmune disorder that would result in a long-term chronic illness. "Idiopathic orbital pseudotumor with a cranial extension," would soon be a phrase I would learn to memorize along with, "I am allergic to azathioprine." I have had 11 rounds of radiation to my brain and right eye. I was on an average of 90 milligrams of prednisone for five years, with several weekends of receiving 3,000 milligrams of steroids intravenously. And I've had several IVIG transfusions. I now have pernicious anemia from all of the medicines I've taken. So I now have to inject B12 into my body once a month in order to stay alive too. I have had cataract surgery in both eyes, also due to all the medication side-effects. And finally, I became post menopausal at 39-years-old because all of the chemo killed my ovaries. My immune system is constantly compromised because not letting my body fight itself is how I stay alive and keep full eye and brain function. I just finished my 52nd chemotherapy infusion and will probably have 300 of them by the time I die (I have 8 infusions a year). That is, if I don't die of cancer before the age of 73. <u>What about you? What's your story? What do you need in order to live and age with dignity?</u></p>
<p>Organizing Image(s)</p> <p>See more HERE</p>	

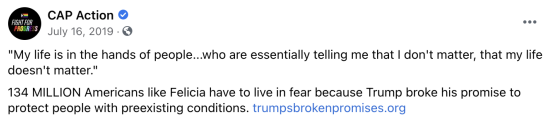

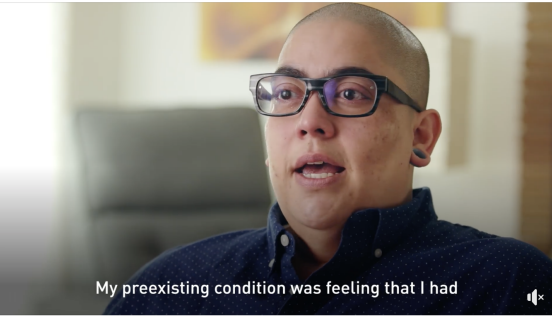


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<p>Mobilizing Stories that motivate folks to take specific action (Part C. 1-5)</p> <p>Awe, Surprise, Sadness/Anger, Vigilance</p>	<p><i>TEAM PEREZ is coming together to help raise funds in Felicia's battle with her idiopathic orbital/cranial pseudotumor (named George).</i></p> <p><i>In August 2012, after finally deciding to take a short break from her 12 years of teaching high school in Los Angeles, Felicia moved to Reno with her family (Emily and dogs). One month later, in September, she began to wake up every morning to an unexplainably swollen right eyelid and headache. After an entire month of no improvement, a roller coaster began. The first MRI in October 2012 showed that she had a tumor in her head behind her right eye. After being refractory to steroids (no improvement), in January 2013 she had a surgical biopsy that determined she had an idiopathic orbital pseudotumor. She quickly became a medical mystery as she continued to be refractory to treatments. Bills for travel to specialists, never ending tests, and medical treatments began to pile up. To date she has had 4 MRIs and the most recent has shown this tumor growing in size and moving towards the right side of her brain. Steroids haven't worked. Radiation didn't work. High dose "at home" chemo once a week for 4 months hasn't worked. IV-IG, an autoimmune transfer, hasn't worked. (Just to give you an idea, she did IV-IG for 5 days with each day costing \$1,200 *with* insurance). We are now a year into this medical mystery (October 2013) and Felicia has begun a new treatment: IV treatment of a chemo drug. Our central goal is to reduce or eliminate the pseudotumor so that it does not become cancer and does not harm Felicia's brain.</i></p> <p><i>Along the way, a number of friends and family have asked how they can help. When we moved we planned on using our incoming for our first house, and nothing else was really planned for. This sudden, unexpected tumor has meant a quick emptying of the savings, the inability for Felicia to work full time, taking out retirement savings, and so on. Someday we will all have the health care we need in a world of peace and justice. But for now, we greatly appreciate any financial help you can offer to help us through this time.</i></p> <p><i>Any and all donations will go towards our \$7,800 yearly out of pocket costs and to expenses that help in the healing process including chiropractic & acupuncture visits. <u>Donate whatever you can and please share this far and wide, because we all deserve to live and age with dignity by any means necessary.</u></i></p>
<p>Mobilizing Image(s)</p>	<p>Thank YOU gofundme donors--FOR LIFE! I will forever be inspired by your swift and humble generosity. And I will take it with me and continue to share with others.</p> <div data-bbox="461 1436 777 1860"> </div> <div data-bbox="786 1478 1386 1793"> </div> <p>WWW.GOFUNDME.COM Help Lucha with her Lucha! Felicia Perez has posted a new update!</p>

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Intention	Text
<p>Advocacy Stories that influence decisions (Part C. 1-4)</p> <p>Anger, Fear, Interest, Optimism</p>	<p><i>My “pre-existing condition” was hopeful. My “pre-existing condition” was free. My “pre-existing condition” was feeling that I had all the opportunities to stay alive. Two weeks ago, I just finished my 35th infusion of rituximab. I can now see some distance between me and death, and then I watch the news.</i></p> <p><i>There are words and there are actions. And when you put those together, they tell the whole story. So do I trust the president?</i></p> <p><i>It's really hard to have hope when people are talking about things they're going to do, but their actions are in deep contradiction with those things. Hearing about the Affordable Care Act no longer existing means everything that I'm doing to get better might not be enough. And that actually my life is in the hands of people who I do not know, who do not know meho are essentially telling me that I don't matter. That my life doesn't matter. That my health doesn't matter. That my day to day quality of life doesn't matter. And that's really hard.</i></p> <p><i>We need to tell the stories of all the different kinds of ways in which the Affordable Care Act affects us because it's in sharing about what's happening in our lives that people realize there are more people in the United States impacted by this than we ever see. How else will my representatives hear my story? If they're not coming to me--I have to come to them in any and every way possible.</i></p> <p>--</p> <p><i>Please share this video far and wide. Let my story be one of many stories that make it hard to because it's easier to kill legislation (a piece of paper) than kill people that we know. <u>We all deserve to live and age with dignity.</u></i></p>
<p>Advocacy Image(s)</p> <p>See PSA Video HERE</p>	<div>      </div>

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Part E. Bonus Story Challenge!!

Sometimes showcasing a depth and breadth to your story can be helpful to move a broader or very particular audience. Remember you want to provide windows in your story or provide mirrors so that your audience recognizes themselves when they share space with you. Review your notes from the second half of Part B for this section.

Intention	Text
<p>Organizing & Advocacy</p> <p>*Story with link to history and other social movements/issues.</p>	<p><i>Wow! Who knew being a literal poster child would be in my future? Who knew having to get a lot of shots and poked all the time would be in my future? Who knew being held like a teddy bear by Senator Harris would be in my future? Who knew your love and support would be in my future?</i></p> <p><i>In honor of Coming Out Day let's be clear, this is how this happened. Coming Out at 14 and slowly but surely getting support from family and friends was the first step on this path of sharing personal stories — because in doing so we show just how common, every day, and human these experiences are. And more importantly that “those people” that politicians speak of or that strangers whisper about, are in fact your friends, your family, your classmates, and your teachers.</i></p> <p><i>So I share my story on behalf of all the Chadwick Boseman's in the world, who didn't feel that this is any of your business and who feel that telling you and your reaction are more than what they need or want to help them heal. I shared because maybe you and yours didn't fill out a form on Facebook about the removal of the ACA and how it would change your life — 4 years ago.</i></p> <p><i>I shared to pay back Ryan White. I shared to pay back Fannie Lou Hamer. I shared to pay back Vito Russo. I shared to pay back Silvia Rivera. And I shared to pay it forward for my niblings, my cousins, my former students, and you.</i></p> <p><i>Singular stories will never be enough. I know that too well. But what I learned when I was 14 is that one story among many can make a difference. So use my story the way that I did... to give a name and a face to just how close these laws are to affecting someone that you know.</i></p> <p><i>It's easier to not support a law, than it is to not support a person. It's easier to want to kill a law, than it is to want to kill a person who you can see and hear.</i></p> <p><i>I appreciate all of your love and support now, before all of this, and moving forward so much.</i></p> <p><i>*This photo is of my eye right after my biopsy. “Yes,” is written above it. It was stitched up and it was healing. It doesn't look like this anymore. And this is why I believe our collective vision and perspective on all things can heal as well.</i></p>
<p>Advocacy Image(s)</p>	