Advocacy: Supporting People With Cancer and Oncology Nurses

Ruth Dennison, RN
Ilisa M Halpern, MPP

Oncology Nursing Society 6th Annual Institutes of Learning
Phoenix, Arizona
November 2005

Effective Advocacy: Testimonials from Practicing Oncology Nurses

Ruth Dennison, RN
ONS Pennsylvania
State Health Policy Liaison

Advocacy: Debunking the Myths

Bet you think:
- Politics are dirty and you can't trust anyone.
- I can't create change and my opinion won't make a difference.
- There is no extra time in my schedule to call legislators.
- I'm a nurse, not a lobbyist.
- My Congressional Member is not active in passing legislation.
- Congress is not addressing my problem at present.
- I am not an expert on legislative issues and I don't know what to write to my Congressman or Senators.
- I can't go to Washington DC and what good will it do to see my Congressman or Senators at home.
- I am intimidated by the legislative process.
- I am a different political party than my Members of Congress, so they don't or won't care.
- I advocate for patients at work. Do I have to advocate for my patients at the Congressional level too?

What do the Legislators say about Nurses?

- They can trust nurses.
- Nurses understand the "big picture" of health issues and concerns.
- Nurses have first-hand, direct bedside experience/understanding of how decisions in Washington affect constituents.
- They are on the side of patients, not profits.
- They are tenacious and reliable!

What Do Nurses Bring To Policymakers?

Oncology Nurses Understand:
- Cancer care and the nursing process
- How a patient experienced the cancer treatment
- "Real-world" health care delivery

Nurses are exceptional at:
- Articulating ideas and issues in an organized way
- Educating, teaching, and advocating
- Troubleshooting and problem solving
- Building teams and consensus
- Expressing empathy, passion, and understanding

Think advocacy is fruitless and that nurses can't make a difference? Think again.

Carole Edwards, RN
State Health Policy Liaison for Alaska
Her husband needed an annual PSA Test and it wasn't covered by insurance.

Carole was motivated enough to discuss the issue with an Alaskan state legislator who was a friend of the family.

She pursued the topic with passion until legislation was passed to ensure that all private health plans in Alaska include PSA Testing.
Carole Edwards, RN
State Health Policy Liaison for Alaska

- Carol was the first Recipient of the ONS Excellence in Oncology Nursing Health Policy and Advocacy Award (2005).
- She was instrumental in legislating financial coverage of care for uninsured women with breast and cervical cancer.
- She continues to work toward increasing funding to address the nursing shortage.
- Presently she serves on the Alaska Nurses Board of Directors.

Think advocacy is fruitless and nurses can’t make a difference? Think again.

What made it work for Carole?

- Leveraging her personal passion;
- Tailoring her message to the audience;
- Using grassroots e-mails to impact the legislature;
- Speaking with confidence to her elected officials; and
- Parlaying her oncology nursing background to impact all nurses and patients in Alaska.

Wendy Smith, MSN, ACNP, AOCN
State Health Policy Liaison for Mississippi

Wendy and 3 nurses lobbied Senators Kennedy & Grassley and Representative Stark.
- They were crucial to the introduction of legislation to change Medicare Hospice rules that allowed for a pilot residential hospice in MS.
- They raised $1.5 million and obtained 10 acres of land to get the hospice built.
- They successfully changed Mississippi state law to allow for narcotic prescription rights for Advanced Practice Nurses.

Think advocacy is fruitless and nurses can’t make a difference? Think again.

What made it work for Wendy?

- Using her enthusiasm and compassion;
- Collaborating with the Mississippi State Nursing Association;
- Taking what she learned at the ONS Leadership Development Institute experience and applying it; and
- Using the media to her advantage.

Think advocacy is fruitless and nurses can’t make a difference? Think again.

...and what about:

- Diane Richardson of Arizona had her Congressional member meet with patients during treatment at her hospital.
- Laura Stemkowski of Connecticut was critical in legislating smoking bans in her state.
- Janet Geeldner of Ohio sponsors an annual legislative meeting of all 8 Ohio chapters.

Think advocacy is fruitless and nurses can’t make a difference? Think again.

My Story:

- I speak from my heart;
- I believe that everyone has the right to appropriate healthcare;
- I am an Oncology Nurse... We are TENACIOUS; and
- I always think outside of the box!

AS A RESULT

- Successful Congressional Breakfast
- Developed Relationships with Congressional Members
Winning Strategies
- Compassion
- Commitment
- Using their nursing skills to promote advocacy
  - Assessment
  - Planning
  - Teaching
  - Evaluating
- Oncology Nursing Society Support
- Using coalitions to leverage resources and were able to speak for many
- Networking colleagues to gather support and encouragement

How Do I Get Started?
- Know your Congressional Members in Washington, DC.
- Learn how to communicate to your Members in Washington DC and at home.
- Register to vote and exercise that right.
- Sign-up for ONSTAT - the ONS electronic grassroots network and respond to action alerts.
- Visit the ONS Legislative Action Center regularly - www.onslac.org
- Learn ONS Health Policies at the ONS LAC.
- Contact your State Health Policy Liaison.
- Contact your local Chapter Legislative Chairperson or Liaison through your Chapter President.

Effective Advocacy:
Oncology Nurses Easily Can Make a Difference and Have An Impact

Ilisa Halpern, MPP
ONS Health Policy Associate
Managing Government Relations Director
Gardner Carton & Douglas
Washington, DC

ADVOCACY
- Patient
- Legislative
- Regulatory
- Media
- Legal

There Ought to be a Law!!
Turning Outrage Into Action

Who Am I to lobby Congress?
I am "just" a nurse.
- The Constitution grants you the right "to petition the government for a redress of grievances."
- Congress Plays Health Professional - you are one and they need your expertise!
- They Work for YOU!
- Washington, DC
  Legislative Staff
  Policy Focus
  District/State Caseworkers & Outreach Staff
  Local Focus/Constituent Services
Key Influences on Public Policy

- Constituents
- Crisis
- Personal Experience
- Research Findings/Data
- Market Forces
- Fiscal Pressures
- Political Ideology
- Special Interest Groups
- Media
- Players/Personalities

CANCER IS UNIVERSAL

- Senator Brownback
- Sens. Helms & Kennedy
- Speaker Hastert
- Presidents Bush I & II

HEALTH IS POLITICAL

- Tobacco
- Stem Cell
- Med Mal Reform
- Medicare “Zero Work Pool”

Congress: The Basics

House
- 435
- Population Based
- More Populous States Have Larger Delegations
- Smaller Delegations
- Serve Two Year Terms
- All 435 Seats Are Up For Election Every Two Years
- 232(R)-202(D)-1(I)

Senate
- 100
- Two Per State
- Both Senators Represent the Entire State
- Serve Six Year Terms and 1/3 of the Senate Is Up For Election Every Two Years
- 55(R)-44(D)-1(I)

Other Players in the Process

- White House: President, Vice President, Office of Management and Budget, Domestic Policy Advisors
- Cabinet Members: Secretaries of Defense, Health and Human Services, Veterans Affairs, Education, etc.
- Congressional Liaisons from Federal Agencies and Political Appointees/Agency Heads

KEY COMMITTEES & CAUCUSES

House
- Appropriations (LHHS)
- Energy & Commerce (Health Subcommittee)
- Ways & Means (Health Subcommittee)
- House Cancer Caucus
- House Nursing Caucus

Senate
- Appropriations (LHHS)
- Health, Education, Labor & Pensions
- Finance Committee
- Senate Cancer Coalition

Other Players in the Process

- White House: President, Vice President, Office of Management and Budget, Domestic Policy Advisors
- Cabinet Members: Secretaries of Defense, Health and Human Services, Veterans Affairs, Education, etc.
- Congressional Liaisons from Federal Agencies and Political Appointees/Agency Heads
**KEY FEDERAL AGENCIES**

- Department of Health & Human Services
  - Centers for Disease Control & Prevention (CDC)
  - Centers for Medicare & Medicaid Services (CMS)
  - Food & Drug Administration (FDA)
  - Health Resources & Services Administration (HRSA)
  - National Cancer Institute (NCI)
  - National Center on Minority Health & Health Disparities (NCMHD)
  - National Institute of Nursing Research (NINR)

**“I’M JUST A BILL, I’M ONLY A BILL…”**

- Bill Introduced (#)
- Reference to Committee
- Reference to Subcommittee
- Reported Out Favorably
  - Full Chamber
  - Repeat in Other Chamber

  Conference Committee
  
  President – t
  
  Enacts or Vetoes

**AUTHORIZATION vs. APPROPRIATING**

- Nurse Reinvestment Act
  - Authorization (August 2002)
  - Expands and Creates Programs
  - Needs To Be Reauthorized (2008)
  - Appropriations (Each Year)
  - Funds Programs
  - Sept. 30th/Oct. 1st Fiscal Year

**CAPITOL HILL: THE REAL DEAL**

- Congress Legislates by Anecdote
  - Compelling Stories Prompt Action
- Members Need to “Hear from Home”
  - Constituents Have An Impact
- Congress is Run by 20 and 30 Year Olds
  - Young Staffers Have Power and Influence, But Need Your Expertise

**YOUR VOICE MATTERS**

Nurses Can Serve as an Advisor or Extension of Staff:

- Gynecologic Cancer Education & Awareness Act - ONS secured the change from “physicians” only, to “physicians, nurses, and key health professionals”
- One Letter = One Law
- One Person = Big Difference

- Megan’s Law
- MADD
- Amber Alert
- America’s Most Wanted
- Rosa Parks

**Cockroach Theory**
COMMUNICATION:
TOP 10 TIPS

1. Be Clear
2. Be Honest
3. Give Evidence (Not too much)
4. Repeat the Point
5. Include a Personal Example
6. Give Local Data
7. Discuss Positive Effects of Taking Action/Consequences of Not Taking Action
8. Be a resource & offer to help
9. Thank/Spank
10. Follow-Up

What Counts?
- All emails, faxes, letters, calls, postcards, petitions, etc. are counted.
- Personal, handwritten letters suggest a high level of priority and importance (send by fax).
- Phone calls and emails allow you to weigh-in quickly on an urgent matter.
- If you establish yourself as an advisor/counselor and a key constituent, your voice will count even more!

What Congressional Staff Say About Constituent Communications

- 48 percent believe the Internet and emails from constituents have made lawmakers more responsive to their voters.
- Almost all Congressional staff “prize” individual missives written by individuals over generic messages.
- Almost all Congressional offices tally and take note of the vast majority of electronic messages they receive, even if they are “mass produced.”
- One letter or call from a known, respected constituent can trump 100s of generic grassroots messages.

Advocates Come In Many Forms & Take Action In Many Ways

- Meetings at District/State Offices
- Meetings on Capitol Hill
- Attendance at Town Hall Meetings
- Testifying at hearings
- Letters to the Editor/Op-ed Pieces
- Establishing a close relationship with elected officials under their STAFF – taking the time to become acquainted with Members of Congress and their staff helps ensure that when you email, call, write, or visit in the future that your input is valued and counted even more

PUTTING ADVOCACY INTO ACTION

- Know Who Represents You
- Register & Vote
- Visit the ONS LAC - www.onslac.org
- Sign up for ONSTAT Today
- Find Local Offices of Your Members of Congress & Visit Them
- Call, Fax, Email Your Policy Makers
- Get to Know the Congressional Staff
- Invite Policymakers to Visit You
- Respond to ONS Action Alerts