



# Patient and Consumer Education: Best Practices

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# What is Pain?

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“Pain is a more terrible lord of mankind than even death itself...”

Albert Schweitzer



# APF Shingles/PHN Survey

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- 74% of respondents did not know where to get information about pain management when they were diagnosed



# APF Opioid Attitude Survey

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- Most were under care of physician for pain management
- 51% felt they had little or no control over their pain
- Typical patient taking opioids still experienced breakthrough pain or severe flares ~2x a day



# APF Opioid Attitude Survey

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- Less than half “strongly agreed” that opioids are safe to take
- 38% “strongly agreed” that it is hard to consistently control pain with opioids



# APF Opioid Attitude Survey

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- Only 31% believed opioids are “very safe”
- 14% believed that opioids are dangerous



# APF Opioid Attitude Survey

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- Taking opioids is perceived as stigma
- Many patients are not getting enough information to manage their pain



# APF Online Support Survey

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- 60% of respondents are disabled because of their pain
- 76% used opioids as primary method of pain management
- Majority reported that severe pain continued to erode quality of life





# Substance Abuse Issues

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- Three groups to be aware of
- Appropriate use of language: addiction is not tolerance is not dependence
- Understand differences and similarities between chronic pain patient and substance abuser
- Patient's rights AND responsibilities



# Address Behavior

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- Management Principles
  - Know laws and regulations
  - Structure therapy to match perceived risk
- Proactive Strategies
  - Communicate goals of treatment
  - Provide written guidelines/treatment contract
  - Assess frequently
  - Avoid stigmatizing labels



# Addressing Behavior

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- Reactive Strategies
  - Collaborate with addiction-medicine community (addiction medicine specialist, substance abuse program, social worker, psychotherapist)



# APF Key Areas of Focus

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- Education & Support
- Public Awareness
- Advocacy
- Research



# Education & Support

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- Pain Information Center
  - Directly responds to consumer requests for information & resources
  - Toll-free Telephone number (888) 615-PAIN (7246)
  - Email service [info@painfoundation.org](mailto:info@painfoundation.org)
  - Average contacts 729 per month



# Pain Information Center

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- Tier 1: Standard information requests
- Tier 2: Increased level of response (complicated requests needing clinical response or mental health intervention)

# APF Website

The screenshot shows the American Pain Foundation website in a Mozilla Firefox browser window. The browser's address bar displays the URL <http://www.painfoundation.org/page.asp?file=Research/default.asp>. The website header features the APF logo, the text "American Pain Foundation" with the tagline "Dedicated to eliminating the undertreatment of pain in America.", and navigation links for "About Us", "Contact Us", and "Join Us". A "Donate Now!" button is also present. The main content area is titled "New & Noteworthy" and features a news item: "APF Begins Study of Online Support Groups". This article includes a photograph of computer keyboard keys and a text block stating: "APF is presently conducting a study about adults with chronic pain who participate in online health information and support services. We are looking for adults over the age of 18 to participate in PainAid, our online support group community. Your involvement in the study will be to participate in PainAid for three months and to complete two sets of questionnaires, one at your enrollment in the study and one at the end of three months. Your name will not be used, and you will not be identified personally in any way. To read more about the study and to sign up, please [click here](#)." Below the article is a link to "ABC News and USA Today Focus on Pain May 7-13, 2005". The left sidebar contains sections for "Info About Pain" (with links to Pain Information Library, Finding Help and Support, Publications From APF, Q & A About Pain, Useful Links About Pain, and Information for the Media) and "Resources" (with links to Online Advocacy Center, PainAid Online Community, and Clinical Trials Center). The right sidebar is titled "Highlights" and contains buttons for "Free Pain Information", "Take Action Now", "Voices of People With Pain", "Veterans and Pain", "Pain and End of Life", and "Feedback and Opinion". The browser's taskbar at the bottom shows the Start button, Netscape Toolbar, and several open applications, including the American Pain Foundation website and a Microsoft Office document.

[www.painfoundation.org](http://www.painfoundation.org)



# Web Stats

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- APF Website
  - 100,087 page views per month
- PainAid
  - 111,214 page views per month
- Advocacy Center
  - 24,677 page views per month



# PainAid Online Support

**American Pain Foundation - Windows Internet Explorer**

http://www.painfoundation.org/PainAid/page.asp?file=page\_home.htm

**American Pain Foundation**

**American Pain Foundation**  
Dedicated to eliminating the undertreatment of pain in America.

**inform**  
Imagine a world without pain...

Home • About Us • Contact Us • Login • Search

**Donate Now!**

**PainAid**

- **FREE eNews Signup!**
- **Conference Room**
- **Discussion Board**
- **Ask The Experts**
- **Veterans Discussion Board**
- **PainAid Guidelines**
- **Staff Directory**
- **Click HERE If You Are In Crisis**

**Info About Pain**

- **Pain Information Library**
- **Finding Help and Support**

**Welcome To PainAid**

Welcome to PainAid, the interactive section of the American Pain Foundation's website. Here you'll find:

- **Conference Rooms: regularly scheduled live chats on a range of issues**
- **Discussion Boards: threaded message boards on a broad range of topics**
- **Veteran's Discussion Board: threaded message boards specially for veterans and their caregivers**
- **Ask-the-Experts: threaded message boards moderated by licensed healthcare professionals**

Topics range from illness-specific pain, conventional and complementary treatments, to depression and family matters, to financial issues such as disability and workers compensation.

This free service is an online forum for people living with pain, and their caregivers. It is staffed almost entirely by highly qualified volunteers with a range of backgrounds, all of whom either live with chronic pain or care for people who do.

**PainAid Mission**

Print View

Done Internet 100%

start | Inbox - Microsoft ... | American Pain Fo... | American Pain Fo... | Microsoft PowerP... | 4:22 PM



# PainAid Online Support

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- Conference Rooms: regularly scheduled live chats on a range of issues
- Discussion Boards: threaded message boards on a broad range of topics
- Veteran's Discussion Board: threaded message boards specially for veterans and their caregivers



# PainAid Online Support

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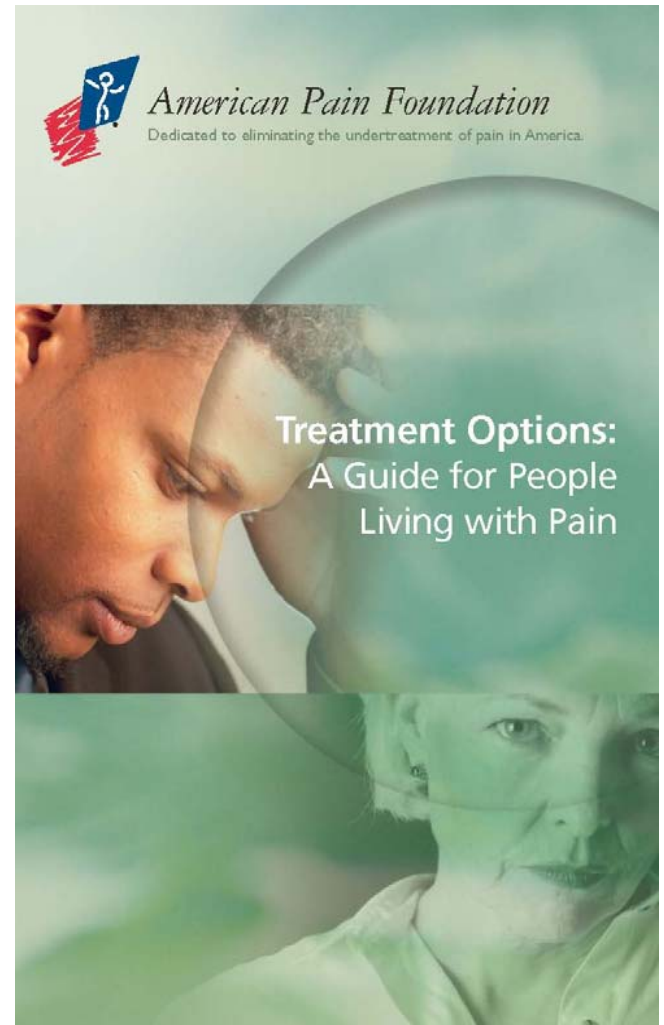
- Ask-the-Experts: threaded message boards moderated by licensed healthcare professionals
- Special topic chat series
- Chat archives
  
- 35,000+ registered participants

# Communications

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New Treatment  
Options book!

Fall, 2006





# What You Can Do

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- Avoid reinventing the wheel
- Collaborate with others to get clear, simple message accross



Thank You!