The alarms that cried wolf

by Cynthia Johnson

Technology has its obvious benefits, but gains in increased efficiency and automation sometimes come with drawbacks. Take medical devices that monitor patients, for example. Their relentless beeping has resulted in a problem known as “alarm fatigue.” Alarms are desensitizing clinicians who hear so many beeps coming from so many devices that they sometimes fail to respond when a true emergency happens.

ECRI Institute of Plymouth Meeting, PA, a nonprofit organization that promotes high standards in healthcare, ranks alarm hazards No. 2 in its Top Ten List of Health Technology Hazards for 2011. Between 2005 and 2010, device manufacturers filed an astounding 216 reports with the FDA on monitor alarm–related deaths.

Facilities vary in how they are prescribing solutions to this growing problem. While some are implementing simple work flow changes, others are looking to manufacturers to develop and improve technology that will help clinicians discern when a device is alerting them to a true emergency as opposed to when it is merely “crying wolf.”

Summit sounds call for action

In October, the Association for the Advancement of Medical Instrumentation held a Medical Device Alarms Summit to assemble vested parties and prioritize the key issues related to the safety and effectiveness of alarms.

The long-term priorities developed at the summit include collecting data, standardizing alarms, and developing alarms that meet the needs of individual patients.

The attendees also developed short-term goals to begin tackling some problems immediately. For example, short-term goals included identifying which alarms are actionable, delivering the right alarm to the right person, and sharing best practices.

“We are at the beginning of a multiyear, long-term project to have clinical data collection, device manufacturer meetings, and regulatory involvement to completely reshape the way alarms are sounded for medical devices,” says David Condra, CEO and chair of Dalcon Communications Systems, headquartered in Nashville. The company focuses on delivering...
IP telephony–based communications solutions to the healthcare industry.

According to Condra, the medical device industry is quite a few years off from making systemic changes that can address the problem at the device manufacturing and regulatory level.

This lack of standardization has caused manufacturers to make their own determinations as to when to sound an alarm, what sounds the alarm makes, and whether the alarm is of high or low priority.

The industry can shorten the amount of time it takes for someone to respond to an alarm by giving them better information about what is causing it, says Condra. This can be accomplished by eliminating the cause of false alarms and lowering the overall volume so alarms aren’t competing for attention with other noises in a facility.

Technology alone is not a panacea

“I've been in hospitals that have between 150 and 200 alarms per shift per patient,” says Pelczarski. A nurse caring for two patients may expect physiologic alarms to alert them an overwhelming 400 times per shift for those two patients. “You really have to look at the entire system in the organization and you have to tailor strategies that will work in that unique context,” she says.

Creating more intelligent devices

Dalcon is responding to these industry needs by marketing a product called Dalcon Alert™. Hospitals can connect patient care devices, such as bed alarm systems, chair fall alert pads, and IV pumps, into their remote alarm monitor.

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When an alarm triggers, the remote alert monitor sends text messages to wireless devices carried by clinicians.

According to John Menees, director of healthcare at Dalcon Communications, the lack of intelligence is a gaping hole in the alarm device industry. Without intelligence, he says, there’s no way to determine the importance of alarms and when and how to notify clinicians. Dalcon’s remote alert monitor allows clinicians to manage alarms with different levels of acuity depending on the patient.

The device also allows facilities to identify nuisance alarms or false alarms that can cause alarm fatigue. For example, a patient can trigger an alarm if he or she moves or coughs. These alarm states typically clear themselves in three to five seconds, says Menees. Customizing the device to wait before sounding can give the device time to clear the alarm on its own.

Menees says preliminary results are showing a decrease in alarms. Patients on ventilators can have alarms that sound 300–400 times during a 12-hour shift. The system has been able to decrease these alarms by 10%–20%.

“If we’re eliminating a ventilator alarm by 10%–20%, you can do the math to see how many we’re missing,” he says.

**Children’s Hospital finds mobile solution**

In 2007, Phoenix Children’s Hospital implemented a solution called Vocera® by San Jose–based Vocera Communications, Inc. The system routes alarms to the appropriate person and bypasses all those who do not need to know about it. It sends mobile alerts to hands-free devices that clinicians wear around their necks.

Deb Green, RN, says she appreciates the hands-free aspect of the Vocera device. “You can be doing something with your patient and not have to pick up a phone and look at it to communicate,” she says.

When the hospital implemented the solution, it worked on distinguishing one alarm from another and only sending the ones that were meaningful to clinicians. “The low-level alarms don’t come across at all,” says Green.

Nurses at the hospital can expect some consistency throughout the facility in the way that Vocera handles certain alarms; however, specific units customize their alarms based on their unique patient population.

The hospital has also put a three-tiered escalation process in place to ensure that someone responds to the alarm. If the first person does not answer an alarm, the alarm rolls to the next person. If that person does not answer, the unit secretary receives notification and must escalate the matter.

“Overall, it has definitely improved communication, but there is a learning curve to it,” says Green. “Nurses must learn to differentiate what the different alarm noises are coming across Vocera.”

**The long and winding road**

According to Barbara Majchrowski of the ECRI Institute’s health devices group, “smart alarms” to combat alarm fatigue may be available in the future. If developed, these devices would allow hospitals to apply algorithms to configure alarms to a particular patient population.

Until improved technology becomes available, Pelczarski advises hospitals to consider actions they can take in the short term, such as making all alarms actionable so that nurses only receive alerts for clinically significant events.

“This can be done by analyzing whether the alarm limit settings are appropriate for individual patients,” says Pelczarski. “You can tailor those alarm settings per patient as appropriate.”

Regardless of how facilities choose to combat alarm fatigue, two things are certain: Alarms are not going to stop beeping, and nurses will likely always think they are receiving too many of them. “I don’t think we will ever be able to send too few alarms,” says Phoenix Children’s Hospital systems analyst Michael Biegen, RN. “We’re always trying to screen out ones that don’t need to be sent, but we have to be careful not to miss one that might be true.”

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**Additional resources**

For more information on the organizations and vendors in this article, visit the following sites:

- Association for the Advancement of Medical Instrumentation: [www.aami.org](http://www.aami.org)
- Phoenix Children’s Hospital: [www.phoenixchildrens.com](http://www.phoenixchildrens.com)
- Vocera: [www.vocera.com](http://www.vocera.com)
- Dalcon: [www.dalcon.com](http://www.dalcon.com)
**New on the net**

**Federal database on doctors is available again**

A database of doctor discipline and malpractice records blocked by the federal government in September was made public again with new restrictions for those who use it. Before downloading the public file of the National Practitioner Data Bank maintained by the U.S. Health Resources and Services Administration, users must agree not to identify individual doctors and to delete or return any data at the request of the agency.

According to a *Post-Dispatch* article, the data bank is a record of malpractice and discipline records intended for hospitals to check doctors’ backgrounds. The public file of the data was stripped of doctors’ names, but has been used for years by reporters and researchers to analyze trends and identify problem doctors by cross-referencing with court and medical board records.

**Mostashari assures patient safety plan sooner than 12 months**

Farzad Mostashari, MD, the national health IT coordinator for the Office of the National Coordinator (ONC) for Health Information Technology at the U.S. Department of Health and Human Services (HHS), said that HHS agencies will work closely to craft a surveillance and action plan to keep patients safer through health IT. According to a *Government Health IT* article, he says it will be done sooner than called for by the Institute of Medicine (IOM).

An IOM report directed ONC to complete its plan within 12 months. In the report, IOM reaffirmed its belief that health IT can improve safety.

**Radiologist tells FDA to change mammography rules**

A radiologist told a federal advisory panel that a woman’s mammography results should tell her whether she has dense breasts so that she’ll know the test may miss a breast cancer diagnosis. According to an article in *The Record*, women with dense breasts are more likely to develop breast cancer and their cancers may be more aggressive based on recent research. Those who’ve already had breast cancer are more likely to have a recurrence if they have dense breasts, but tumor cells may be impossible to distinguish from normal cells on their mammograms because both show up as white areas.

**Expert tells Congress that EMRs are rarely encrypted**

A privacy expert told lawmakers that electronic medical records (EMR), which the Obama administration would like to see widely used, are rarely encrypted, so a data breach could be triggered by the simple theft of a laptop or misplaced thumb drive.

According to a Reuters article, regulations require healthcare providers to report data breaches unless the data lost had been encrypted.

**IOM issues 10 HIT recommendations for patient safety**

Health IT (HIT) is said to be key to improving quality and safety. According to a HealthLeaders Media report, there’s an underappreciated chance that the use of computers might cause harm.

A report by the Institute of Medicine (IOM) states that examples of HIT-induced harm that can result in serious injury and death include dosing errors, failing to detect fatal illnesses, and delaying treatment due to poor human-computer interactions or loss of data. The report provided one example of an elderly patient who was harmed by an overdose of potassium chloride because of flaws in a computerized physician order entry system. The physician used the coded entry field to write the prescription order, but tried to limit the dose by writing in the comment box.
EHR vendors endorse medical error reporting system

Recognizing that electronic health records (EHR) can and do cause medical errors, a group of EHR vendors has agreed to support a patient safety organization’s online system for reporting adverse events.

According to an InformationWeek article, the HIMSS EHR Association, an affiliate of the Healthcare Information and Management Systems Society, announced that it is prompting the use of EHRvent, a year-old reporting system developed by the iHealth Alliance. The iHealth Alliance is a patient safety organization convened by major U.S. medical societies, medical malpractice insurers, other patient safety advocates, and liaisons from the FDA.

In addition to information about illnesses, EMRs contain patients’ dates of birth, Social Security numbers, and other data that are valuable to identity thieves.

Hospitals fall short on MU

The latest research from the Healthcare Information and Management Systems Society is reporting that from February to September 2011 there has been a 16% increase (from 25% to 41%) in the number of eligible hospitals saying that they are likely to meet criteria for Stage 1 of meaningful use (MU). However, 53% of hospitals say they cannot meet 10 or more of the 14 core requirements set out in Stage 1.

According to an InformationWeek article, the survey reflects that hospitals increasingly recognize the need to adopt health IT, but that they also face many challenges as they attempt to transition from paper-based medical record charts to digitized medical records.

ONC delays permanent EHR certifiers’ program

The Office of the National Health Coordinator for Health IT (ONC) will delay the launch of the permanent program for certification of electronic health records.

Trinity HealthCare cuts mortality rate with new app platform

Trinity HealthCare, the fourth largest Catholic healthcare system in the country, has put a great deal of creativity and man hours into a platform it calls Genesis. According to an InformationWeek article, Genesis includes 28 computer applications from nine vendors and touches virtually every major clinical and revenue process at the hospital.

Implementing Genesis will require the tightly choreographed integration of new systems with multiple legacy applications, including laboratory, picture archiving, communication, and enterprise resource planning systems. More than 60 real-time and batch interfaces were activated during conversion.

As a result, Trinity has seen a 44% drop in severity-adjusted mortality rates. That means more than 2,600 lives are saved across the system annually. Similarly, since going live with Genesis, emergent medications are delivered 40% faster and nurses spend 8% more of their time at the bedside.

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New on the net

health records (EHR) until mid-2012 to coincide with the anticipated final rule for Stage 2 of meaningful use and standards and certification criteria.

According to a Government Health IT article, ONC also said it needed more time to assemble and approve testing labs and authorized certifying bodies. Previously, ONC intended to sunset its temporary program at the end of the year and open the permanent and more comprehensive program on or around January 1.

Nursing CIOs play greater role

As healthcare providers install and build out electronic health records systems, nurses are demanding leadership roles in IT projects. According to an Information Week article, hospitals across the country appear to be responding by creating the position of chief nursing information officer (CNIO).

According to a survey from executive search firm Witt-Kieffer, 70% of multi-hospital systems and 82% of hospitals that are part of multi-hospital systems surveyed last year said that they had a CNIO or equivalent.

A majority of freestanding hospitals, integrated delivery networks, and academic medical centers also have hired a lead nursing informaticist. Seventeen percent said they planned to bring in a CNIO in the next year or two.

FDA approves innovative, noninvasive heart valve

Federal health officials have approved a first-of-its-kind artificial heart valve that can be implanted without major surgery. According to an Associated Press article, the valve offers a new treatment option for patients who are too old or frail for the chest-opening procedure currently used.

The FDA said that it approved Edwards Lifesciences’ Sapien heart valve, which can be threaded into place through a major artery that runs from the leg to the heart. Cardiologists say the new approach will help old, sickly patients who cannot undergo open heart surgery, which has been used to replace heart valves for decades.

Few hospitals qualify for digital funds

Although hospitals are eligible for billions of dollars in federal stimulus money for digitizing records to save money and improve the quality of healthcare, just one in 10 is ready to meet government standards to qualify for the funds.

According to an article in The New York Times, a study by the Healthcare Information and Management Systems Society (HIMSS) shows that just 10% of the nation’s hospitals are now ready to address all 14 core measures. The government is requiring that hospitals meet these measures before they can get extra payments from the federal Medicare health insurance program for the elderly or Medicaid health insurance for the poor.

Illinois physician database launches

Illinois patients can now research their doctors online using a database launched by the state. According to a Chicago Tribune article, the site is attempting to take the guesswork out of choosing a physician by making it easier for patients to access information about the state’s 46,000 licensed physicians and surgeons.

The database can be accessed through the Department of Financial and Professional Regulation’s website at idfpr.com. There, patients can learn about a doctor’s educational background and training, determine what type of insurance they accept, and find out what languages are spoken in the office. The site also includes information regarding criminal convictions, revoked hospital privileges, and disciplinary actions against the doctor by regulators in Illinois and other states.
Children get some of the same cancers that adults get; however, early treatment makes it possible for physicians to cure many patients. The most common types of children’s cancers are leukemia, brain tumors, lymphoma, and sarcoma. The Internet contains many helpful websites that provide information on these types of cancer and their impact on the youngest of patients.

The Leukemia & Lymphoma Society (www.lls.org) is a nonprofit health organization whose website contains information on these diseases, tips for caregivers, and information for the newly diagnosed.

St. Jude Children's Research Hospital (www.stjude.org) is a renowned pediatric treatment and research facility for children with cancer. The hospital’s website contains information about childhood cancers, cancer survivor resources, and a Cure4Kids section with education on cells, cancer, and healthy living for kids, parents, and teachers.

Lastly, the National Cancer Institute site (www.cancer.gov) contains information about cancers, treatment options, tests, and a unique handbook titled *Young People With Cancer*.

### Focus: Cancer in children resources

A number of resources about cancer in children are described and reviewed in the following pages, as listed in the index below, using the five-star system to rate each on content, interface, and style.

#### American Cancer Society

**www.cancer.org**

Ratings: Content: **** Interface: ***** Style: *****

The American Cancer Society (ACS) is a nationwide, community-based voluntary health organization dedicated to eliminating cancer as a major health problem. The organization works to prevent cancer, save lives, and diminish suffering from cancer through research, education, advocacy, and service.

You can navigate this site using the top-level navigation links. Some of the links expand to reveal additional menu options. You can also click on links on the site’s home page to access featured content, such as links to frequently searched topics, news articles, and links to individual sections of the site. To access information about cancer in children, click Cancer in Children from the Select a Cancer Type drop-down menu.

Key features of this site include:

- Information about the differences between cancers in children and adults
- Statistics related to childhood cancer
- A list of the most common types of childhood cancers
- Causes, risk factors, and prevention information
Information about early detection, diagnosis, and how childhood cancer is staged
Treatment options for childhood cancer
Advice on coping with your child’s diagnosis
Advice for talking about cancer with family, friends and healthcare workers
Patient stories
Links to additional resources and references

Unique elements: The site has a Circle of Sharing tool on its site that helps cancer patients and their caregivers get personalized information about the disease and share that information with family and friends.

Comments: The site is available in English and Spanish.

Cost: Free. Certain areas may require free registration.

RSS XML link: www.cancer.org/rss?IdcService=GET_INTHENEWS_FEED

Keywords: cancer in children, leukemia, brain tumors, lymphoma, soft tissue sarcoma, American Cancer Society, ACS.

Centers for Disease Control and Prevention
www.cdc.gov

Ratings: Content: ***** Interface: ***** Style: *****

The Centers for Disease Control and Prevention (CDC) is a federal agency of the U.S. Department of Health and Human Services. The CDC provides the public with reliable health information, such as data and statistics on diseases and conditions, emergencies and disasters, environmental health, healthy living, travelers’ health, and workplace safety.

You can navigate this website using the A–Z index at the top of the home page. You can also access featured content on the site’s home page, such as news articles, event information, and publications. You can find information about cancer in children in the Data and Statistics section by selecting By Demographic. You can also look up cancer types individually on the site.

Key features of this site include:

Unique elements: The site contains podcasts on cancer topics such as sun safety and smoking cessation.

Unique elements: The site contains information in English and Spanish.

Cost: Free. Users can subscribe to the site to receive news and information using the link on the home page.

RSS XML link: Visit www.cdc.gov/podcasts/rss.asp for a complete list of feeds.

Keywords: cancer in children, leukemia, brain tumors, lymphoma, soft tissue sarcoma, Centers for Disease Control and Prevention, CDC.

Children’s Hospice International
www.chionline.org

Ratings: Content: **** Interface: *** Style: ***

Children’s Hospice International (CHI) works to ingrain the hospice concept into pediatrics so that it isn’t considered a separate specialty, but an integral aspect of care for children and adolescents. The nonprofit organization was founded in 1983.

You can navigate this site using the top-level navigation links. You can also click on links on the site’s home page to access featured content, such as news articles.

Key features of this site include:

Unique elements: The society has a Circle of Sharing tool on its site that helps cancer patients and their caregivers get personalized information about the disease and share that information with family and friends.

Comments: The site is available in English and Spanish.

Cost: Free. Users can subscribe to the site to receive news and information using the link on the home page.


Keywords: cancer in children, leukemia, brain tumors, lymphoma, soft tissue sarcoma, American Cancer Society, ACS.
**Unique elements:** The site contains links to additional hospice resources for children.

**Comments:** To learn how to become a member, click the Become a Member link.

**Cost:** Free. Click the Stay Informed link to receive information from the organization.

**RSS XML link:** None.

**Keywords:** hospice, end-of-life care, palliative care, Children’s Hospice International, CHI.

### CureSearch for Children’s Cancer

**www.curesearch.org**

**Ratings:** Content: **** Interface: **** Style: *****

CureSearch for Children’s Cancer is a national nonprofit foundation whose mission is to fund and support children’s cancer research and provide resources to all those affected by children’s cancer. The organization raises funds for research conducted at more than 175 hospitals.

You can navigate this site using the links on the home page. You can also click on links on the site’s home page to access featured content, such as news articles.

Key features of this site include:

» Information about cancer diagnosis and treatment options

» Survivorship guidelines

» A glossary of cancer-related terms

» A family handbook in English and Spanish

» Information about clinical trials

» Advice on coping with cancer emotions

» How to become involved with the organization through fundraising, advocacy, and volunteerism

**Unique elements:** The site has a link that expands to list all the types of childhood cancer. You’ll find it in the middle of the home page.

**Comments:** Users can sign up to receive the organization’s newsletter by clicking the link on the home page.

**Cost:** Free.

**RSS XML link:** None.

**Keywords:** leukemia, brain tumors, lymphoma, soft tissue sarcoma, CureSearch for Children’s Cancer, CureSearch for Children’s Cancer.

### KidsHealth.org

**www.kidshealth.org**

**Ratings:** Content: ***** Interface: ***** Style: *****

KidsHealth is part of the Nemours Foundation’s Center for Children’s Health Media. The website contains information about health, behavior, and development from before birth through the teen years.

When you enter the site, you need to select Parent. From there, you can navigate this site using the left-hand navigation links. To access information about cancer in children, type that in the Search field and select the topic you want to learn more about. The Parents section also contains a Cancer section.

Key features of this site include:

» Information about different cancer treatments and therapies

» Tips on handling emotional issues surrounding cancer

» Details about common medical tests

» Information about specific types of cancer, tumors, and blood disorders

» Personal stories

» Answers to FAQs
Unique elements: The site contains an informative cancer guide.

Comments: The site contains information in English and Spanish.

Cost: Free. Users can sign up to receive the free KidsHealth weekly newsletter, which contains medically reviewed content.

RSS XML link: None.

Keywords: cancer in children, leukemia, brain tumors, lymphoma, soft tissue sarcoma, Nemours Foundation, KidsHealth.org.

**Leukemia & Lymphoma Society**

www.lls.org

Ratings: Content: ***** Interface: ***** Style: *****

The Leukemia & Lymphoma Society is a nonprofit health organization dedicated to funding blood cancer research and providing education and patient services.

You can navigate this site using the top-level navigation links. Some of the links expand to reveal additional menu options. You can also click on links on the site’s home page to access featured content, such as patient stories.

Key features of this site include:
- Information on diseases such as leukemia and lymphoma
- Advice on managing your cancer
- Where to go to get information and support
- Information for caregivers
- Information for researchers and healthcare professionals, including continuing medical education
- Free educational materials
- News articles
- Clinical trials information

- Information for the newly diagnosed
- Links to social networking pages

Unique elements: Users can chat with employees at the society using the site’s Live Chat feature.

Comments: The site contains information in English and Spanish.

Cost: Free.


Keywords: cancer in children, leukemia, brain tumors, lymphoma, soft tissue sarcoma, Leukemia & Lymphoma Society.

**National Cancer Institute**

www.cancer.gov

Ratings: Content: ***** Interface: ***** Style: *****

Established in 1937, the National Cancer Institute (NCI) is part of the National Institutes of Health (NIH) and the U.S. Department of Health and Human Services. NCI’s main responsibilities include coordinating the National Cancer Program, conducting and supporting cancer-related research, training physicians and scientists, and disseminating information about cancer.

You can navigate this site using the top-level navigation links. You can also click on links on the site’s home page to access featured content, such as information regarding types of cancer and cancer topics. To access information about cancer in children, click Cancer Topics, then click Childhood Cancers.

Key features of this site include:
- A dictionary of cancer terms
- A drug dictionary
» Information about treatment options, such as surgery, chemotherapy, radiation therapy, and immunotherapy
» Information regarding the side effects of cancer
» How to manage cancer-related complications
» Information about psychosocial concerns
» Risk factors and prevention advice
» Methods of childhood cancer screening and testing
» Cancer incidence, mortality, and survival statistics

Unique elements: The site contains a handbook titled *Young People With Cancer: A Handbook for Parents.*

Comments: The site is available in English and Spanish and contains information for healthcare professionals and patients alike.

Cost: Free.


Keywords: cancer in children, leukemia, brain tumors, lymphoma, soft tissue sarcoma, National Institutes of Health, NIH, National Cancer Institute, NCI.

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**The National Children’s Cancer Society**

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

Ratings: Content: ***** Interface: **** Style: *****

The National Children’s Cancer Society (NCCS) works to improve the quality of life for children with cancer and their families worldwide. The society serves as a financial, emotional, and educational resource for those in need.

You can navigate this site using the top-level navigation links. Some of the links expand to reveal additional menu options. You can also click on links on the site’s home page to access featured content, such as event information and conferences.

Key features of this site include:

» Information about the assistance the society offers
» Content for healthcare providers
» Publications
» Survivor stories
» Links to additional resources
» Videos on topics such as survivorship

Unique elements: The site recently launched a new online community.

Comments: Users can sign up to receive e-updates from the society. Click on the link in the banner to sign up.

Cost: Free.

RSS XML link: None.

Keywords: cancer in children, leukemia, brain tumors, lymphoma, soft tissue sarcoma, The National Children’s Cancer Society, NCCS.

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**Pediatric Brain Tumor Foundation**

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

Ratings: Content: ***** Interface: **** Style: *****

The Pediatric Brain Tumor Foundation (PBTF) is a nonprofit charitable organization that is working to find the cause of and cure for childhood brain tumors. The foundation supports research, increases public awareness, and helps aid early detection and treatment.

You can navigate this site using the top-level navigation links. Some of the links expand to reveal additional menu options. You can also click on links on the site’s home page.
to access featured content, such as news articles and links to social networking pages.

You can navigate this site using the top-level navigation links. Some of the links expand to reveal additional menu options. You can also click on links on the site’s homepage to access featured content, such as its patient of the month feature. To access information about cancer in children, click Clinical Programs, then select Comprehensive Cancer Center.

Key features of this site include:
- A list of cancer center programs
- Education and training information
- Medicine and science news
- Cancer center collaborations
- A list of upcoming seminars
- Information about a variety of brain tumors, leukemias, and lymphomas
- Links to social networking pages
- Information about the hospital
- Childhood cancer survivor resources

Unique elements: St. Jude’s has a site called Cure4Kids that provides education on cells, cancer, and healthy living for kids, parents, and teachers.
Comments: The site is available in a number of languages.
Cost: Free.
RSS XML link: www.stjude.org/stjude/rss/stjude_news_rss.xml
Keywords: cancer in children, leukemia, brain tumors, lymphoma, soft tissue sarcoma, St. Jude Children’s Research Hospital.
Focus: Dementia resources

Many diseases can cause dementia, including Alzheimer’s disease, stroke, and frontotemporal degeneration. While there is no cure, there are medications that can improve symptoms and slow the track of the disease.

If you’re looking for information about Alzheimer’s disease, you’ll want to consult the Alzheimer’s Foundation of America website (www.alzfdn.org). The site contains information about Alzheimer’s and related diseases, statistics, videos, and advice for caregivers.

The National Institute of Neurological Disorders and Stroke website (www.ninds.nih.gov) contains content on many types of dementia. You’ll find a list of treatment options, research updates, and publications.

Lastly, the Association for Frontotemporal Degeneration website (www.theafd.org) provides users with information on the causes and treatments for frontotemporal degeneration. The Healthcare Professionals section contains resources to help clinicians understand the diagnostic criteria for the disease, which is often hard to discern from Alzheimer’s.

A number of dementia resources are described and reviewed in the following pages, as listed in the index below, using the five-star system to rate each on content, interface, and style.

Alzheimer’s Association
www.alz.org
Ratings: Content: ***** Interface: **** Style: ****

The Alzheimer’s Association (AA) is a global voluntary health organization that focuses on Alzheimer’s care and support. According to its website, it is the also the largest, private, nonprofit funder of Alzheimer’s research. The association’s mission is “to eliminate Alzheimer’s disease through the advancement of research, to provide and enhance care and support for all affected, and to reduce the risk of dementia through the promotion of brain health.”

You can navigate this site using the top-level navigation links. Some of the links expand to reveal additional menu options. You can also click on links on the site’s home page to access featured content, such as local resources, fundraising opportunities, and news articles.

Key features of this site include:
» Information about Alzheimer’s disease and related dementias
» Facts and figures associated with these diseases
» A list of signs to look for in patients

Index: Dementia resources

Alzheimer’s Association ................................. 13
Alzheimer’s Foundation of America ..................... 14
Alzheimer’s Disease Education and Referral
(ADEAR) Center ........................................ 15
American Health Assistance Foundation.............. 15
The Association for Frontotemporal Degeneration .. 16
Huntington’s Disease Society of America .......... 17
Lewy Body Dementia Association, Inc. .............. 17
National Institute of Neurological Disorders and Stroke . 18
National Stroke Association .......................... 18
Parkinson’s Disease Foundation ........................ 19
Risk factors for Alzheimer’s disease  
How physicians diagnose these diseases  
Treatment options for patients  
Some myths surrounding Alzheimer’s  
Links to clinical studies  
Research updates  
Publications  
Personal stories  
Advice on caring for someone with dementia  
Links to additional resources

Unique elements: The Living with Alzheimer’s section on the site contains helpful resources, including message boards. There’s also a section for children and teenagers who may have loved ones with the disease.

Comments: The site is available in additional languages, including Spanish and Chinese.

Cost: Free.

RSS XML link: None.

Keywords: dementia, Alzheimer’s disease, Alzheimer’s Association, AA.

Alzheimer’s Foundation of America
www.alzfdn.org

Ratings: Content: ***** Interface: **** Style: ****

The Alzheimer’s Foundation of America (AFA) was founded by a consortium of organizations to ensure quality of care and excellence in service to individuals with Alzheimer’s disease and related illnesses, their caregivers, and their families. The foundation’s mission is “to provide optimal care and services to individuals confronting dementia, and to their caregivers and families—through member organizations dedicated to improving quality of life.”

You can navigate this site using the top-level navigation links. Some of the links expand to reveal additional menu options. You can also click on links on the site’s home page to access featured content, such as news articles and helpful links.

Key features of this site include:
- Information about the foundation
- Information about Alzheimer's and dementia
- Warning signs
- A list of symptoms
- Information regarding life expectancy for patients
- Research progress updates
- Statistics

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> Information about the cost of these diseases
> Early detection information, including descriptions of memory screenings
> Advice for caregivers
> Information about related illnesses, such as Huntington’s disease, Lewy body dementia, and Parkinson’s disease
> Links to social networking pages

Unique elements: The site contains videos of the foundation’s telethon as well as celebrity public service announcements.

Comments: The site has information available in English and Spanish.

Cost: Free. You can sign up to receive the AFA e-Newsletter by clicking the link at the bottom of the home page.

RSS XML link: None.

Keywords: dementia, Alzheimer’s disease, Alzheimer’s Foundation of America, AFA.

Alzheimer’s Disease Education and Referral (ADEAR) Center
www.nia.nih.gov/alzheimers

Ratings: Content: ***** Interface: **** Style: ****

The Alzheimer’s Disease Education and Referral (ADEAR) Center website provides current information and resources about Alzheimer’s disease from the National Institute on Aging (NIA).

Key features of this site include:
> Information about the disease
> Statistics related to Alzheimer’s in the United States
> Life expectancy information for those living with the disease
> A description of dementia and how it relates to Alzheimer’s disease
> A fact sheet
> Links to additional information
> Information about the possible causes of the disease
> Prevention advice
> Symptoms associated with Alzheimer’s disease
> Information on how physicians diagnose patients
> Treatment options
> Content specifically targeted to caregivers and healthcare professionals
> Clinical trials resources

Unique elements: The site contains a captioned video explaining the Alzheimer’s disease process. You’ll find it in the General Information section.

Comments: The site contains information in English and Spanish.

Cost: Free.

RSS XML link: None.

Keywords: dementia, Alzheimer’s disease, National Institutes of Health, NIH, National Institute on Aging, NIA, Alzheimer’s Disease Education and Referral Center, ADEAR.

American Health Assistance Foundation
www.ahaf.org

Ratings: Content: ***** Interface: **** Style: ****

The American Health Assistance Foundation (AHAF) is an international, nonprofit organization working to find cures for age-related degenerative diseases. The foundation funds research and disseminates information to the public.

You can navigate this site using the top-level navigation links. You can also click on links on the site’s home page to access featured content, such as links to the foundation’s social networking pages. Click on the Alzheimer’s Disease...
Research link on the home page to access information about the disease.

Key features of this site include:

- A description of the disease
- Advice for living with Alzheimer’s
- Links to additional resources
- Advocacy information
- Information about research grants
- Event information
- A list of symptoms
- Risk factors for the disease
- Advice for caregivers
- Publications and newsletters

Unique elements: The site contains an Ask the Expert feature. You’ll find the link on the left-hand side of the section.

Comments: The site contains memory games to help boost cognitive function.

Cost: Free.

RSS XML link: Visit www.ahaf.org/general/rss-subscriptions.html for a complete list of feeds.

Keywords: dementia, Alzheimer’s disease, American Health Assistance Foundation, AHAF.

The Association for Frontotemporal Degeneration

www.theaftd.org

Ratings: Content: ***** Interface: **** Style: ****

The Association for Frontotemporal Degeneration (AFTD) is a nonprofit organization created in 2002 to advocate for more funding into the causes and treatments for the disease, as well as to provide caregivers and patients with a central place to find information and support.

You can navigate this site using the top-level navigation links. Some of the links expand to reveal additional menu options. You can also click on links on the site’s home page to access featured content, such as news articles.

Key features of this site include:

- Information about the association
- Information regarding advocacy efforts around the disease
- A description of FTD, including clinical presentation
- How physicians discern FTD from Alzheimer’s disease when making a diagnosis
- Managing the disease, since there is no known cure
- The prognosis for patients who have FTD
- Information about specific FTD disorders, such as behavioral variant FTD, Pick’s disease, and others
- The importance of having a brain autopsy
- AFTD’s research initiatives
- Support services and resources for individuals and families
- How physicians diagnose patients with FTD, including tests that they may conduct
- How genetics play a part in a person getting FTD
- A calendar of events

Unique elements: The site contains a Healthcare Professionals section that provides resources to help clinicians understand the diagnostic criteria, treatment, and course of FTD.
Comments: The site contains information for the newly diagnosed. You’ll find a link to this content from the home page.

Cost: Free.
RSS XML link: None.
Keywords: dementia, Alzheimer’s disease, frontotemporal degeneration, The Association for Frontotemporal Degeneration, AFTD.

Huntington’s Disease Society of America
www.hdsa.org
Ratings: Content: **** Interface: **** Style: ****

The Huntington’s Disease Society of America (HSDA) is a nonprofit, voluntary health agency that is working to find a cure for Huntington’s disease. The society provides support, information, and educational services. It also offers resources and guidance, and promotes and supports research.

You can navigate this site using the top-level navigation links. You can also click on links on the site’s home page to access featured content, such as news and announcements. If you search the site using the term “dementia,” you will find articles about how the disease causes cognitive decline in patients.

Key features of this site include:
» Information about the society
» Research updates
» Grant applications for researchers
» Clinical trials information
» Advocacy information
» Information about the stages of the disease

Caregiver advice
» Treatment guidelines
» Personal stories by those affected by the disease
» Links to additional resources
» News articles

Unique elements: The site contains webinars for caregivers.
Comments: The site contains a timeline of key events in HD research.
Cost: Free.
RSS XML link: None.
Keywords: dementia, Huntington’s disease, Huntington’s Disease Society of America, HSDA.

Lewy Body Dementia Association, Inc.
www.lbda.org
Ratings: Content: ***** Interface: **** Style: ****

The Lewy Body Dementia Association, Inc. (LBDA) is a nonprofit organization dedicated to raising awareness of the Lewy body dementias; supporting patients, their families, and caregivers; and promoting scientific advances.

You can navigate this site using the top-level navigation links. The home page also has Quick Links to frequently accessed content. You can click on links on the site’s home page to access featured content, such as news articles and event information.

Key features of this site include:
» A description of LBD
» How physicians diagnose patients with the disease
» Symptoms associated with LBD

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Treatment options for those living with the disease
Research progress updates
Publications
An e-newsletter
Links to additional resources
Clinical trials information
Continuing medical education information
Links to local and virtual support groups
Caregiver stories and resources
An online discussion forum
A chat room
Information for professionals about diagnosis and treatment, such as the toll the disease takes on families, DLB and PDD diagnostic criteria, and more

Unique elements: The site’s multimedia section contains webinars, interviews, and transcripts.

Comments: The association has pages on many social networking sites.

Cost: Free.

RSS XML link: None.

Keywords: dementia, Lewy body dementia, Lewy Body Dementia Association, Inc., LBDA.

National Institute of Neurological Disorders and Stroke
www.ninds.nih.gov
Ratings: Content: **** Interface: **** Style: ****

The mission of the National Institute of Neurological Disorders and Stroke (NINDS) is to reduce the burden of neurological disease. The institute conducts research, provides grants and fellowships, and collects and disseminates information. It is one of the National Institutes of Health (NIH).

You can navigate this site using the top-level navigation links. You can also click on links on the site’s home page to access featured content, such as links to news articles, advocacy information, and online tools. To access information on dementia, click D in the Disorders A–Z index, then select from the dementia topics listed: dementia, dementia - multi-infarct, dementia - semantic, dementia - subcortical.

Key features of this site include:
» A description of dementia
» Treatment options for those with dementia, including medications
» The prognosis for those with dementia, including information on disorders that can cause dementia
» Research updates
» Clinical trials resources
» Links to additional resources

Unique elements: The site contains many dementia-related publications.

Comments: The site is available in English and Spanish.

Cost: Free.

RSS XML link: None.

Keywords: dementia, Alzheimer’s disease, Huntington’s disease, National Institutes of Health, NIH, National Institute of Neurological Disorders and Stroke, NINDS.

National Stroke Association
www.stroke.org
Ratings: Content: **** Interface: **** Style: ****

The National Stroke Association (NSA) works to reduce the incidence and impact of stroke by developing education and programs focused on prevention, treatment, rehabilitation, and support. It is a national, nonprofit organization.

You can navigate this site using the top-level navigation links. Some of the links expand to reveal additional menu options. You can also click on links on the site’s home page to access featured content, such as links to news articles and the association’s social networking pages. The site contains information on vascular dementia, which is a common complication resulting from stroke that involves the loss of cognitive function.
Key features of this site include:

- A description of vascular dementia
- Statistics related to the complication
- How physicians diagnose patients with vascular dementia
- Treatments for vascular dementia, which reduce the risk of additional strokes

Unique elements: The site contains many publications, including brochures, fact sheets, and newsletters.

Comments: Users can sign up to receive news and information from the association by entering an e-mail address in the relevant field on the home page.

Cost: Free.

RSS XML link: None.

Keywords: dementia, vascular dementia, National Stroke Association, NSA.

Parkinson's Disease Foundation

www.pdf.org

Ratings: Content: ***** Interface: **** Style: ****

Founded in 1957, the Parkinson's Disease Foundation (PDF) works on disease research, education, and public advocacy. The foundation funds scientific research and supports people living with the disease through educational programs and services.

You can navigate this site using the top-level navigation links. Some of the links expand to reveal additional menu options. You can also click on links on the site’s home page to access featured content, such as links to news articles and answers to FAQs.

Key features of this site include:

- A helpful publication titled Coping With Dementia: Advice for Caregivers
- Research funding information and research results
- A description of Parkinson's disease
- Symptoms of the disease
- Possible causes for the disease
- Information about medications and treatments
- Clinical trials resources
- Statistics
- Educational publications
- Newsletters and e-newsletters
- A blog
- Webcasts
- Information for healthcare professionals, such as free patient education materials, courses, and resources listed by profession
- Advice for living with the disease, including coping with the diagnosis, managing symptoms, and support systems
- An ask the expert feature

Unique elements: The site contains online seminars. Users can also browse past online seminars.

Comments: Users can sign up to receive news and information from the foundation by clicking the Join Our Mailing List link on the site.

Cost: Free.

RSS XML link: None.

Keywords: dementia, Alzheimer's disease, Huntington's disease, vascular dementia, Parkinson's Disease Foundation, PDF.
The Children’s Cancer Research Fund is a national nonprofit that is working to find a cure for childhood cancers. The organization provides funds to the University of Minnesota, a national leader in pediatric cancer research, for research and training related to prevention, treatment, and cure of childhood cancer. The organization also educates the public about childhood cancer and supports quality of life programs for pediatric cancer patients and their families.

You can navigate this free site using the top-level navigation links. Some of the links expand to reveal additional menu options. You can also click on links on the site’s home page to access featured content, such as links to frequently searched topics, news articles, and links to stories of hope about children who have had cancer.

The site has a unique library of resources to help users understand childhood cancer. Click the Learning Center link on the home page to access this information.

Key features of this site include:

» Details about the organization

» Information about the types of research the organization funds and the researchers who conduct it

» News articles

» Event information

» A section about understanding childhood cancer

» Information about treatments and therapies

» Patient and family resources

» A section about surviving cancer

» A list of volunteer opportunities, including a site that allows users to set up their own fundraising page for cancer research

» Articles about childhood cancers

» Signs and symptoms of cancer in children

» Statistics related to childhood cancer, including five-year survival rates

» A glossary of associated medical terms

» Information about common childhood cancers, including acute lymphoblastic leukemia, brain tumors, Wilms’ tumor, sarcomas, and many others

Users can access newsletters and register to receive free updates from the organization by clicking the link at the top of the home page.

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