

Living Well with Epilepsy

Report of the 1997 National Conference on Public Health and Epilepsy



Centers for Disease Control and Prevention
American Epilepsy Society
Epilepsy Foundation
National Association of Epilepsy Centers

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I. INTRODUCTION

A. Epilepsy: A Life-altering Chronic Condition

Epilepsy is a central nervous system disorder that is characterized by unprovoked, recurrent seizures that disrupt communication among brain cells. Although epilepsy is often amenable to clinical treatment through medications, surgery, and diet, it can be a life-altering condition for persons affected by it. These life-altering effects result in part from the unpredictability of the seizures, which can curtail, to some degree, daily activities such as driving, school attendance, and employment. Persons with epilepsy and seizures also contend with the discrimination and misunderstanding of those around them—the results of decades of stigma and misunderstanding about the disorder and its consequences.

Even with its unique manifestations, epilepsy shares characteristics with a variety of chronic conditions. It affects many aspects of a person's life, it is relatively difficult to detect, and it tends to contribute to morbidity rather than mortality.

B. The Public Health Approach

Epilepsy shares another characteristic with other chronic diseases: a relatively recent inclusion within the public health fold. Although public health's roots are in the control of infectious disease, the more recent past has demonstrated that the same tools that have helped control infectious diseases can be effectively deployed against chronic diseases, disabilities, and injuries. With its dual focus on monitoring the health of populations through epidemiology and on preventing the occurrence or complications of disease and disability, public health can contribute to ongoing efforts to understand epilepsy's course and to treat its immediate and long-term consequences more effectively.

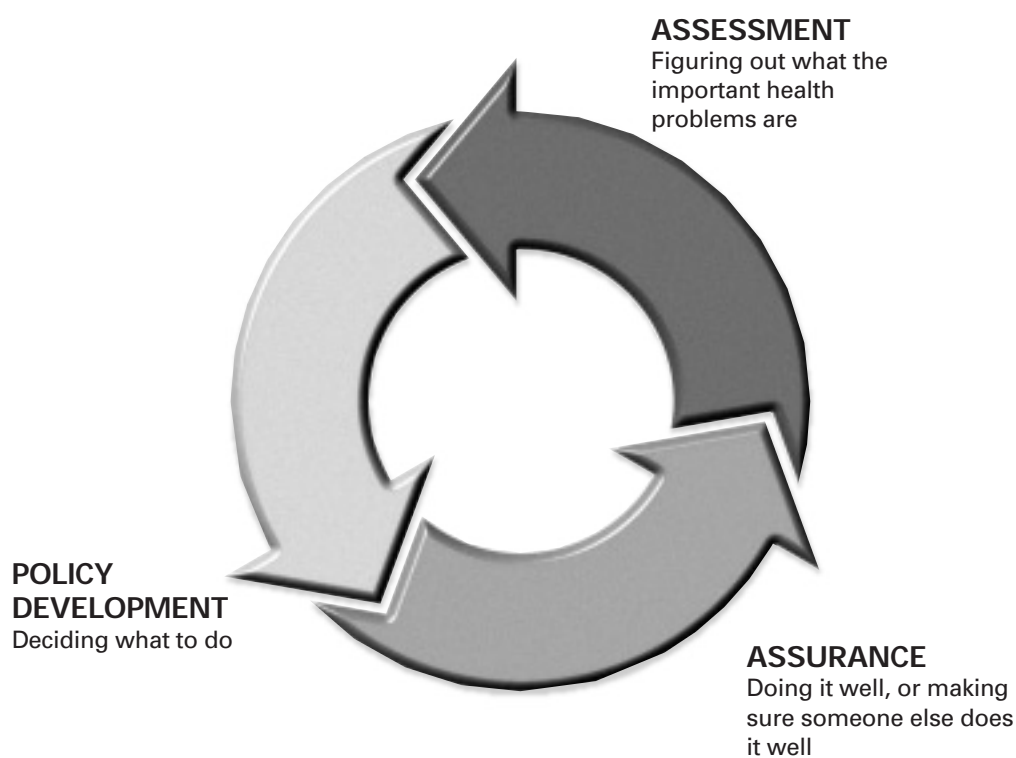
In 1988, the Institute of Medicine published a monograph entitled *The Future of Public Health*, which delineated three core functions of public health: assessment, policy development, and assurance. These overlapping functions describe the spectrum of public health activities which range from surveillance and other epidemiological tools that are used to detect and monitor trends, to advocacy, health promotion and education, and data-driven interventions.

As illustrated in Figure 1, the core functions of public health overlap and contribute to one another in an ongoing cycle.

In late 1994, the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) within the Centers for Disease Control and Prevention (CDC) convened a group of experts representing the epilepsy treatment and advocacy communities to help the agency shape a public health agenda for epilepsy. This approach, informed by the core functions and building on CDC's work with other chronic diseases and conditions, led to Living Well with Epilepsy, the first national conference on public health and epilepsy.

As the health care system moves increasingly toward models of disease management, systematic diagnosis and treatment guidelines, and cost-driven policies (such as increased out-patient care rather than in-hospital care), public health has a critical leadership role to play. This role includes convening major constituents, defining the scientific base, and ensuring a rational approach to policy decisions related to chronic disease—all objectives of *Living Well with Epilepsy*.

Figure 1¹
PUBLIC HEALTH CORE FUNCTIONS



¹ Adapted from the Washington State Department of Health's *Public Health Improvement Plan* (1994) and the Institute of Medicine's *The Future of Public Health* (National Academy of Sciences, 1988).

II. CONFERENCE PARTICIPANTS, GOALS, AND WORKGROUPS

A. Co-sponsors and Participants

*Living Well with Epilepsy*² was held on September 10–11, 1997, in Orlando, Florida. Co-sponsored by CDC, the American Epilepsy Society, the National Association of Epilepsy Centers, and the Epilepsy Foundation of America, the conference brought together:

- specialists in public health disciplines of prevention, epidemiology, health education, and health promotion
- clinicians who treat persons with epilepsy
- advocates for persons with epilepsy and their families
- researchers
- representatives of different health care settings (such as managed care organizations and specialty diagnostic and treatment centers)
- health care consumers.

Conference contributors and workgroup participants are identified in Appendix A.

B. Conference Goals

The public health, clinical, and advocacy communities represented among the participants share common research interests, constituencies, and a strong commitment to improving the lives of persons affected by epilepsy. In addition to the general goal of bringing these communities together, the conference co-sponsors sought to achieve three specific goals:

- **assess what is currently known** about seizures and epilepsy
- **identify critical gaps** in the scientific basis for effective seizure recognition and treatment
- **determine potential strategies** for overcoming barriers to optimal health and functioning for persons with seizures and epilepsy.

C. The Charge to Conference Workgroups

These three goals generally parallel the core functions of public health. To explore and reinforce the public health model's application to epilepsy, conference participants were divided into three workgroups that examined current epilepsy issues in the context of public health.

Table 1 shows the match between the charges to each workgroup and the core functions of public health.

² This conference shares its title with *Living Well With Epilepsy*, a book written by Robert J. Gumnit, M.D. (1997). As a member of the Scientific Program Committee and Workgroup A, Dr. Gumnit participated in the planning and implementation of the conference.

**Table 1
CORE FUNCTIONS OF PUBLIC HEALTH AND
CONFERENCE WORKGROUPS**

<i>Core Function</i>	<i>Workgroup Title and Charge</i>
Policy Development →	A Workgroup A: Early Detection and Treatment Identify clinical issues and priority questions for clinical research
Assessment →	B Workgroup B: Epidemiology and Surveillance Examine current data systems and quality, appropriate surveillance and data collection, and measurement gaps
Assurance →	C Workgroup C: Living Well with Epilepsy Identify and promote effective policies, programs, and communication strategies

In addition, each workgroup considered the cross-cutting issue of how care for people with epilepsy should be organized.

Each workgroup considered issues raised in preliminary background papers and made specific recommendations about priority issues for CDC and its partners to consider. Summaries of each group’s recommendations are included in the following pages.

In addition to advancing the research and intervention agendas most relevant for epilepsy, the workgroups’ deliberations may help establish a model for effective control of chronic conditions that may not be among the leading contributors to mortality, yet still profoundly affect the morbidity, health care costs, and quality of life of those affected by the condition. Indeed, the conference’s co-sponsors and participants share the hope that the lessons learned from the effective control and prevention of seizures and epilepsy can influence the control and prevention of other chronic conditions that interfere with optimal health for millions of Americans.

A

Workgroup A

III. WORKGROUP A: EARLY DETECTION AND TREATMENT

A. Charge

Workgroup A considered critical clinical issues, especially diagnostic approaches and treatment, as well as priority questions for clinical research. The group's consensus statement summarizes the therapeutic goal in treating epilepsy:

No seizures + No side effects = Control.

B. Overview of Workgroup A Background Paper

To provide a context for the recommendations that follow, the background paper for Workgroup A, entitled *Evaluation, Diagnosis, and Treatment of Epilepsy: Critical Issues in Delivering Appropriate Care*, is briefly summarized below.

Understanding Epilepsy

The seizures that characterize epilepsy reflect many different causes—some known, but most unknown. In children, important causes of seizures are birth and neonatal injuries, vascular insults, congenital or metabolic disorders, head injuries, infection, neoplasia, and heredity. In adults, the most common identifiable causes are vascular lesions, head trauma, drug or alcohol abuse, neoplasia, infection, and heredity. However, for both children and adults, a definite cause cannot be determined in many cases.

The likelihood of experiencing the onset of seizures is highest in the first year of life, then decreases in adolescence. Following adolescence, the incidence of epilepsy remains relatively constant until about age 60, after which it rises dramatically. The risk of ever having a seizure is about 9%. About 3% of the population will be diagnosed with epilepsy after having more than one seizure. In the United States, more than 2 million people are being treated for epilepsy. Many more cases are likely, but undetected.

Classification and Diagnosis

An accurate diagnosis of epilepsy is the first step in effectively managing the disorder. In 1989, the Commission on Classification and Terminology (under the auspices of the International League Against Epilepsy) developed a widely accepted classification system based on seizure type and epilepsy syndromes. Seizure type refers to whether the seizure is partial, generalized, or unclassified, with many finer distinctions in each category. Epileptic syndromes are categorized according to whether they are localization-related (focal, local, or partial), generalized, indeterminate, or special. EEGs, along with clinical histories, physical examinations, CT scans, and MRI, are used to determine the epilepsy syndrome.

Only half of patients with epilepsy are diagnosed within the first 6 months of the disorder's onset; it takes 5 years for 85 percent of patients to be diagnosed. Early, accurate diagnosis after the first seizure is critical because the second seizure can cause greater harm. In addition, a

prolonged period without seizure control increases risks for social, psychological, and neurological difficulties that could otherwise be prevented or alleviated.

Treatment of Epilepsy

Initiating treatment with medication after a single seizure is controversial, since it is difficult to determine with certainty whether a first seizure is a unique occurrence or the first sign of chronic epilepsy. Such decisions may secondarily affect other areas of life, such as driving and employment.

Once the clinician has determined that a patient's seizures are not the result of an underlying treatable problem, antiepileptic drug therapy is initiated, preferably with a single agent and at the lowest possible dose.

For the majority of patients, drug treatment is effective; however, as with other chronic conditions, the physician and patient must find the specific therapy that offers the greatest seizure control and the fewest and most tolerable side effects. Key treatment issues include non-adherence with antiepileptic regimes (which occurs with 40 to 60 percent of adult patients and 25 to 75 percent of pediatric patients) and patient self-management, such as monitoring seizures and psychosocial reactions to the fear of seizures.

Approximately 20 percent of patients who receive antiepileptic drug therapy experience recurring seizures. Partial seizures are considered to be more likely to be intractable than other forms of epilepsy. Options in these situations include referral to specialized epilepsy centers for additional medication management, use of nonpharmacologic treatment devices, surgery, or some combination of the above.

No seizures
+ No side effects
= Control

C. Summary of Workgroup A Recommendations

Workgroup A generated a comprehensive list of research questions raised by the background paper and by the group's discussion of it during the meeting.

From this list, group members ranked priority research questions in three categories:

• The First Seizure—Priority Research Questions

Research on the first seizure should address how its psychosocial impact can be minimized. This topic includes attention to the components of an appropriate diagnostic evaluation offered to a person having a first seizure, attention to the impact that a diagnosis of seizure has on individuals and their families, effective consumer education and the most effective modes for delivering it, and techniques for motivating patients to learn and participate in decision making.

• Epilepsy in General—Priority Research Questions

The research agenda for epilepsy overall should identify which outcome measures (e.g., seizure control, cognitive function, psychosocial status) define successful treatment.

• **Organized Systems of Care—Priority Research Questions**

Priority research questions for organized systems of care included the following:

- how to provide efficient and effective care and education for persons with epilepsy
- how to facilitate the interaction between experts and primary care providers
- which services (e.g., medical, educational, social) benefit persons with epilepsy
- how these services can be integrated how integrated multi-disciplinary services can be provided within organized systems of health care.

IV. WORKGROUP B: EPIDEMIOLOGY AND SURVEILLANCE

B

Workgroup B

A. Charge

Workgroup B examined the following topics:

- **classifications** of epilepsy and other seizure disorders
- **methods** used to ascertain epilepsy and seizure disorders in epidemiologic studies
- **understudied populations**
- patterns of **co-morbidity** between epilepsy and other chronic diseases
- areas of **etiologic attribution** requiring further research
- mechanisms to address **gaps in epidemiologic knowledge** and assessment of epilepsy.

B. Overview of Workgroup B Background Paper

The background paper for Workgroup B was entitled *Living Well with Epilepsy: Epidemiology*. It outlined key issues slated for discussion at the conference.

Classifications of Epilepsy and Other Seizure Disorders

Working definitions of seizures and their causes are critical for epidemiologic studies. Currently, seizures are classified using one of the following criteria for prevalence and incidence studies, each of which has limitations:

- self-reported seizures or epilepsy from surveys (either accepted as reported or followed up with clinical examinations and record reviews)
- International Classification of Disease discharge diagnoses (ICD-9 codes)
- prescription records for antiepileptic drugs
- medical record reviews.

Methods Used to Ascertain Epilepsy and Seizure Disorders in Epidemiologic Studies

North American prevalence studies reviewed for this paper show rates ranging from 2 to 15 per 1,000 persons, with most clustered in the range of 5 to 8 per 1,000 persons. Since incidence studies require monitoring of new cases over time rather than a cross-sectional survey, there are far fewer incidence than prevalence studies of epilepsy and other seizure disorders. Other difficulties with assessments of epilepsy trends include varying definitions of active cases and the inclusion of non-epilepsy seizures in some surveys.

A potential source of data is the large-scale data sets maintained by managed care systems. Although managed care organizations offer a defined population and standardized, relatively thorough medical information, they also have some limitations for population-based studies.

SECTION

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The limitations include selective recruitment of healthier, employed populations; high turnover; and the absence of some demographic information, such as ethnicity.

Understudied Populations

Descriptive epidemiology of epilepsy by region, socioeconomic status, or ethnicity is limited, with ethnicity a particularly neglected variable. However, age-specific incidence studies reveal that age is the strongest demographic risk factor for epilepsy: incidence is highest in the first year of life, decreases in adolescence, and rises dramatically after the age of 60. “As the U.S. population ages,” the authors of the Workgroup B background paper note, “epilepsy will become more and more a disease of the elderly.” This observation suggests that the elderly constitute another population neglected by epidemiologic studies, but warranting closer scrutiny.

“As the U.S. population ages, epilepsy will become more and more a disease of the elderly.”

Patterns of Co-morbidity between Epilepsy and Other Chronic Diseases

Epilepsy is connected to two distinct types of co-morbidity: the many neurologic insults that *lead to* epilepsy (causing approximately a third of all cases) and therefore co-exist with the disorder, and the diseases whose incidence is higher among people with epilepsy *as a consequence of* the seizures or their treatment.

In the latter category are **sudden unexplained deaths** and **injuries** related to seizures (such as fractures or drowning). At this point, the direct connection, if any, between epilepsy and the major **illnesses of aging** remains unclear.

Prevalence estimates of **psychiatric disorders** among those with epilepsy vary widely, but depression is believed to be the most common of these. Epidemiologic research on the prevalence of psychiatric disorders, symptoms, and reactions to psychosocial barriers and stresses is lacking.

Current studies suggest that persons with epilepsy have a higher prevalence of **disability**, but additional studies are needed that link disabilities to type of seizures, their frequency, and associated neurologic conditions. In addition, disability measures that incorporate measures of independence, social participation, mobility, and interpersonal relationships are needed.

Areas of Etiologic Attribution Requiring further Research

Key issues in etiologic attribution include measures of secondary epilepsy (because of disagreements about which central nervous system insults cause epilepsy, and for how long) and the inadvertent contributions to epilepsy from increased survivorship of traumatic brain injuries and infectious diseases, such as encephalitis and cysticercosis.

Mechanisms to Address Gaps in Epidemiologic Knowledge and Assessment of Epilepsy

Increasing the professional and clinical awareness of epilepsy requires addressing the interests of the medical professions and government agencies that fund research and interventions. For a number of reasons, greater public awareness is also important—to reduce stigma and misunderstanding, recruit special populations for studies (such as those of pregnancy and epilepsy), and generate training opportunities for persons interested in the epidemiology of seizure disorders.

C. Summary of Workgroup B Recommendations

1. Develop and disseminate **consistent working definitions** of epilepsy, cases, seizures, and intractability. (Some may require modifications from global definitions.) Once these definitions are developed, develop training workshops for epidemiologists to disseminate consistent definitions and to encourage their use.
2. Identify appropriate **outcome measures** of epilepsy and seizure disorders for use in epidemiologic research and public health surveillance, especially for the following areas:
 - quality of life
 - cost
 - disability and function
 - co-morbidities.
3. Examine dimensions of epilepsy among **at-risk populations** by:
 - gender
 - residence (rural, urban)
 - age group
 - socioeconomic status
 - ethnicity.
4. Investigate the feasibility of various **approaches to population based surveillance**, including use of :
 - statewide surveillance systems
 - managed care datasets
 - registries
 - geographic information system (GIS).
5. Explore **alternative funding sources** for epilepsy-related studies that address:
 - role of neurologists and epileptologists
 - cost-benefit analyses
 - public attitudes
 - cost of illness
 - access to care.
6. Develop **confidentiality** safeguards that will protect patients without impeding population-based studies.

V. WORKGROUP C: LIVING WELL WITH EPILEPSY

A. Charge

Workgroup C addressed the impact of perceived, actual, hidden, or unrecognized stigma that prevents persons with seizures and epilepsy from enjoying the fullest quality of life. The group focused particularly on the current state of health communication in epilepsy to address its perceived stigma.

B. Overview of Workgroup C Background Paper

The background paper for Workgroup C was entitled *Living Well with Epilepsy: The Roles of Health Communication*. The three-part paper examined health communication in the public health context, the need for health communication to address epilepsy issues, and lessons learned from a selective review of health communication literature. To frame the group's recommendations, highlights of the paper are provided below.

Health Communication and Epilepsy

A 1996 survey conducted by the Epilepsy Foundation of America asked persons whose lives are affected by epilepsy to identify their primary concerns. At the top of the list was “insufficient public awareness” that led to misconceptions, insensitivity, and discrimination—in other words, the stigma that people with epilepsy experience from the general public, health care providers, school personnel, and others.

Although public perceptions about epilepsy are slowly changing for the better, misconceptions are still common. These misconceptions contribute not only to negative attitudes, but also to gaps in knowledge about first aid for a person experiencing a seizure.

Key Principles for Effective Health Communication Practice

Health communication is defined as “the crafting and delivery of messages and strategies, based on consumer research, to promote the health of individuals and communities.”³ During the past decade, a wide range of health communication campaigns have been undertaken to raise awareness, increase knowledge, influence and reinforce attitudes and social norms, and support actions and behaviors. (Literature describing many of these campaigns and interventions, and their results, were reviewed for the background paper.)

Key principles that have emerged from these campaigns include the following:

- **significant resources** should be committed to program planning and development
- **target audiences** must be carefully delineated to guide decisions about messages and products
- messages and materials must be of **high quality** to compete successfully

³ Roper, WL. 1993. Health Communication Takes on New Dimensions at CDC. *Public Health Reports* 108(2):179-183.

- **multiple ways** to reach and influence target audiences should be considered and used
- the **Internet** and other electronically supported communications should be used, because they offer unprecedented opportunities to improve access and rapidly reach audiences (with some limitations)
- strategic decisions should consider a **combination** of audience, channels, and message design so that each part of the equation contributes to the desired effect
- **partnerships** can contribute complementary strengths and resources
- **evaluation** is critical for achieving and measuring success
- long-term, **sustained commitments** are needed to yield lasting effects.

Health Communication Responses to Epilepsy Needs

The following planning questions were suggested to guide development of appropriate health communication interventions for persons affected by epilepsy:

- What are the most important **barriers** to quality of life from the affected individuals' points of view? ("Persons with epilepsy" should be more carefully defined to clarify different needs, such as the information and support needs of the recently diagnosed.)
- What **policies and practices** can be altered to help break down these barriers?
- **Who must be influenced** to change the policies and practices?
- **What must occur** to achieve the desired changes among target audiences?

The workgroup's consideration of these questions yielded recommendations in each category, which are summarized below.

C. Summary of Workgroup C Recommendations

1. **Stigma and the factors that contribute to it** should be addressed as the top priority in epilepsy self-management and advocacy. Factors include:
 - lack of awareness
 - lack of timely, complete, and accurate information
 - misperceptions
 - the broad, varied spectrum of disability among people with epilepsy
 - over-concern about safety and over-protection limiting choices and options
 - learned helplessness
 - social tolerance for stigma and discrimination
 - insufficient research on stigma and psychosocial aspects of epilepsy
 - liability concerns
 - fear.
2. Actions and plans to address stigma must **include people with epilepsy** and/or family members and care givers in the planning process and must be inclusive of all cultures they are designed to reach.

3. Actions or plans to address stigma must include **planned health communication strategies** designed for **specific audiences**.
4. The top three priority audiences for health communication campaigns to counter epilepsy-related stigma are:
 - school personnel
 - persons with epilepsy and their parents or care givers
 - health care gatekeepers, including nurse practitioners and school nurses
5. Communication strategies for these audiences should be designed to yield **specific results**, as shown in Table 2.

**Table 2
PRIORITY TARGET AUDIENCES AND DESIRED RESULTS OF PLANNED
HEALTH COMMUNICATION STRATEGIES**

<i>Priority Audience</i>	<i>Desired Results</i>
School Personnel	<ul style="list-style-type: none"> • development of school-based curricula with continuing education units (CEUs) for school personnel • implementation of policies that help schools address curriculum and liability concerns • improved awareness to reduce stigma and social isolation
Parents and Care Givers	<ul style="list-style-type: none"> • parents provide full age-appropriate information to their children with epilepsy (“fully open” communication) • parents promote safety and independence in children with seizures (avoiding over-protection)
Health Care Gatekeepers	<ul style="list-style-type: none"> • increased awareness of signs and symptoms of seizures, the diagnostic process, and when to refer
Persons with Epilepsy and Their Care Givers	<ul style="list-style-type: none"> • increased understanding of epilepsy, treatment options, and resources; increased investment in self-management

6. Health communication strategies must be based on the following prioritized criteria:

- **impact:** whether the change with each target audience is likely to have a sufficient impact on the problem to justify the effort required
- **relevance:** how the audience is relevant to persons with epilepsy, public health, and the problem
- **feasibility:** whether the change within the audience is achievable, and whether it can be attained through health communication strategies
- **leverage:** whether the audience can facilitate change in larger communities and populations (e.g., opinion leaders, stakeholders)
- **connection:** whether the audience can be reached easily by at least some partners engaged in the effort.

VI. CDC ACTIVITIES RELATED TO RECOMMENDATIONS

Several current initiatives are under way in response to the workgroups' recommendations.

A. Organized Systems of Care

CDC and the Agency for Health Care Policy and Research (AHCPR) are collaborating to assess the feasibility of developing a framework for organizing the clinical processes necessary to provide optimal care for persons with epilepsy. Development of the framework will depend on the end result of several preparatory steps:

1. A multi-disciplinary **meeting of key stakeholders** (such as epilepsy specialists, neurologists, primary care providers, health care systems representatives, consumers, and consumer advocates) will help define lines of inquiry for a literature review and special analyses.
2. A **literature review** will examine models of care for chronic diseases and consider how these findings might be applied to the care of persons with epilepsy.
3. Building on the input of key stakeholders and literature review, a comprehensive evidence report will be developed that includes findings on criteria for effective care for persons with epilepsy. Topics will likely include:
 - appropriate diagnostic approaches
 - criteria for assessing adequate treatment
 - assessment of outcome measures for treatment
 - support for psychosocial issues related to epilepsy
 - issues in organizing and integrating care (especially information that can be used by primary care providers and non-epilepsy specialists to judge when referral to more specialized care is appropriate).

The draft evidence report will be submitted for peer review before a final version is prepared.

B. Health Communication Strategy for Adolescents with Epilepsy

CDC is working with partners to develop a health communication plan to help adolescents with epilepsy make informed decisions about what details of their condition to share and with whom.

Health communication planning tasks are under way to develop a fuller understanding of the target audience and of the messages that will be effective with adolescents.

C. Managed Care Collaboration

CDC has established an informal managed care network of partners interested in responding to the challenge of improving care of persons with epilepsy.

VII. CONCLUSION

The *Living Well with Epilepsy* conference made a substantial impact on public health and epilepsy by initiating a process to:

- highlight the importance of epilepsy and seizures as a public health problem
- bring together participants from the major sectors—epilepsy community, clinical providers, public health, and organized systems of care—to ensure optimal health for persons with epilepsy
- stimulate active discussion across disciplines, fields, and interests
- define a prioritized strategy that encompasses the spectrum of disease—prevention through appropriate care and treatment to effective health promotion and reduction of disabilities
- use the dramatic changes under way in health care organization to improve the care of persons with epilepsy and seizures
- define the scientific foundation and identify critical gaps in what we know
- make recommendations that will be used by CDC to guide the NCCDPHP epilepsy program from this point forward.

A major contribution to be expected from the CDC epilepsy program is the development of a model for effective control of chronic conditions with low prevalence and mortality. Although low prevalence conditions together account for substantial disease burden and health care costs, expectations for large future public programs to address each condition is unrealistic. CDC will use the workgroups' recommendations, along with input from the broad national public health community to set the epilepsy program into the context of the national public health agenda.



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