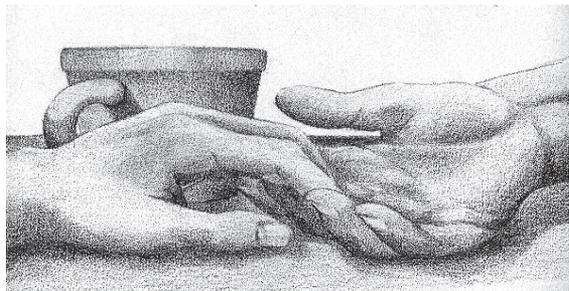
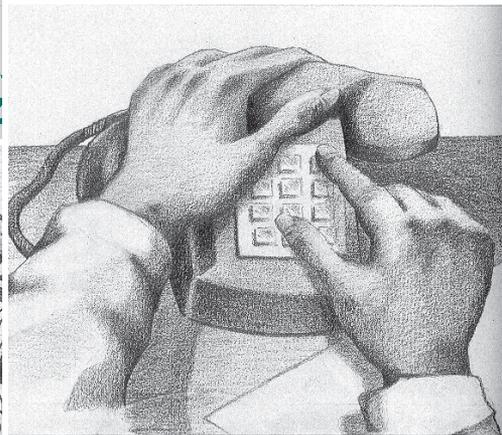




# *Standards for Public Health Nurses*



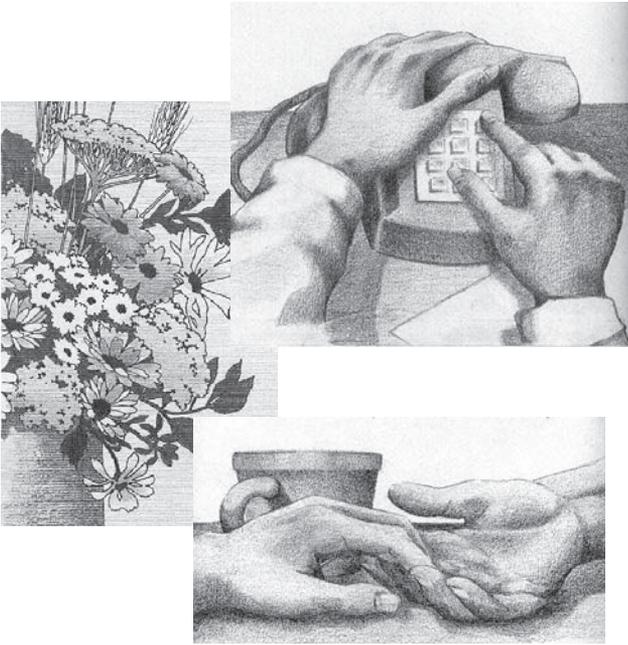
CALIFORNIA  
**SIDS**  
PROGRAM

SUDDEN INFANT  
DEATH SYNDROME

CALIFORNIA DEPARTMENT  
OF HEALTH SERVICES MCH

## Sudden Infant Death Syndrome

# *Standards for Public Health Nurses*



## **Sudden Infant Death Syndrome**

The California Nurses Association Nursing Practice Commission has reviewed the Sudden Infant Death Syndrome Standards of Practice for Public Health Nurses in California and supports these standards as a model to serve nurses and health care professionals practicing with this population. These standards were unanimously endorsed by the California Nurses Association, Board of Directors on September 18, 1994.

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## **Introduction**

Sudden Infant Death Syndrome (SIDS) is defined as the sudden death of an infant, usually under one (1) year of age, which remains unexplained after the performance of a complete postmortem investigation including an autopsy, an examination of the death scene, and a review of the case history.

California law designates the County Health Officer as the person responsible for provision of services to SIDS families. Each California health jurisdiction has developed its own system for SIDS case management according to local conditions.

California legislation has addressed many of the problems faced by SIDS families, caregivers, and the system designed to help them. The public health nurse is identified as a “trained public health professional” able to provide care and support for families and caregivers who have experienced the sudden death of an infant. This legislation reinforced a need for the development of standards of nursing practice to assure similar nursing care in California for SIDS families/caregivers.

Standards are authoritative, measurable statements which define the nursing profession’s accountability to the public and the patient outcomes for which nurses are responsible as found in the “Standards of Clinical Practice” (1). They guide professional nursing practice and provide the framework for the evaluation of practice. They also serve as a frame of reference for policy, procedure and protocol development, education, and planning. Concern for the quality of services constitutes the heart of any profession’s responsibility to the public. Standards of practice provide measures for evaluating quality of care. Standards reflect the current state of

knowledge in the field and therefore are provisional, dynamic, and subject to testing and subsequent change.

These standards are based on the previous work of the California Association of Public Health Nurses (CAPHN) completed and approved by their Board of Directors on April 17, 1992.

### **Legislative/Historical Perspective**

As early as the 1950's some researchers were interested in the phenomenon of "crib death", but it was not until the 1960's that an organized effort began to address SIDS. SIDS was first defined as a distinct medical entity in 1969. Federal hearings were held during 1972 and 1973 regarding SIDS.

The Sudden Infant Death Syndrome Act of 1974 (Public Health Law 93-270) authorized the disbursement of federal grant dollars and set the conditions for the development of information and counseling services in each state. When separate SIDS grant monies were discontinued, the SIDS project was incorporated into the federal Maternal and Child Health Block Grant.

California State Law (Statutes of 1974; Chapters 453, 1212, and 1259) provides the legal base for the management of SIDS in California. This legislation mandates autopsy of SIDS cases with exceptions specifically defined. The law requires the County Coroner to notify the County Health Officer (or designee) of suspected cases of SIDS within twenty-four (24) hours. The Health Officer (or designee) has the responsibility to provide information to all parties involved in the SIDS case.

The law also requires the State Department of Health Services to



inform County Health Officers about current information regarding SIDS and to report annually to the legislature the number of autopsies performed pursuant to the act and the number of cases determined to be SIDS.

The "California SIDS Information and Counseling Project" was developed as the State's response to the federal mandates and was administered by the California State Department of Health Services, Maternal and Child Health Branch. The project goals were to maintain high quality services to SIDS families through county systems; to assist professionals in upgrading their knowledge and skills; and to raise public awareness regarding SIDS. Project staff worked with local health departments and coroners' offices to develop a system for providing services to families and other bereaved persons.

In January 1987 the State Department of Health Services Maternal and Child Health Branch contracted with the California Association of Public Health Nurses (CAPHN) to provide many of the SIDS services formerly provided by the State.

By 1989, legislation (Statutes of 1989; Chapters 955, 1111, 1112, and 1118) amended the Health and Safety Code to require the California Department of Health Services to contract for the provision of SIDS educational and training programs for specified persons, including public health nurses; and the production and distribution of literature to specified populations of people who interact with parents and caregivers following a death from SIDS. It required the Commission on Peace Officers Standards and Training and the Emergency Medical Services Authority to include information on SIDS in their trainings. A nine member SIDS Advisory Council which includes public health nurses was also

established. The legislation also required the California Department of Health Services to develop a protocol for performing an autopsy in any case where an infant has died suddenly and unexpectedly.

In 1991, legislation, (Statutes 1991; Chapter 268) amended the Health and Safety Code to state that the designated agent of the health officer shall be a “public health nurse or social worker who is knowledgeable about the incidence of Sudden Infant Death Syndrome and the care and support of persons who have experienced a death of this nature and who has basic counseling skills.” This legislation also required contact with the person or persons who had custody and control of the child, including foster parents and child care providers, within three working days of notification by the reporting agent.

### **The Role of the Public Health Nurse in Sudden Infant Death Syndrome**

Prior to the authorization of the Sudden Infant Death Syndrome Act of 1974, PHNs were minimally involved in providing services to families who had experienced the death of a child from SIDS. The extent of these services varied widely by health jurisdiction. Since 1974 almost all Health Officers in California have chosen to delegate their SIDS responsibilities to Public Health Nursing.

Assessment, information, counseling and case management are the cornerstones of PHN services following a SIDS death. The PHN role



also includes functioning as a case manager and working as an integral member of an interdisciplinary team. This coordinated effort allows the PHN to be responsive to the needs of families and caregivers, and prevents fragmentation, gaps, and duplication of services.

## **The Preparation and Responsibility of the Public Health Nurse**

In California, the PHN is a registered nurse with a PHN certificate who has specialized education and certification combining Nursing and Public Health theories. Many are also Master's prepared. The PHN has the unique ability to work independently in the home, clinic, and the community setting, providing care across the cultural, age, and social continuum.

## STANDARDS OF CARE

### STANDARD I. ASSESSMENT

***The Public Health Nurse collects, assesses, and documents client health data.***

#### *Measuring Criteria*

1. Following a death from SIDS the family/caregiver, foster parent and/or child care provider is contacted for the purpose of conducting an assessment within three (3) working days of receiving notice from the coroner or other reporting agency.
2. Pertinent data are collected using effective interviewing techniques, behavioral observations, and psychosocial assessments.
3. Data collection occurs in an environment such as the home that is conducive to assessment of the family/caregiver, foster parents and/or other child care providers.
4. The data collection process provides for systematic gathering, evaluation, and communication of information from the health care providers, first responders, coroners, and family/caregivers.
5. Relevant data are documented and retrievable and serve as the basis for nursing diagnosis and development of a plan of care.



6. Assessment of individual family members/caregivers includes SIDS knowledge, support needs, individual and cultural coping patterns, strengths, weaknesses, support systems, stages of the grief process, and spiritual beliefs.
7. Sources of data for assessment may include:
  - a. Family composition and interaction.
  - b. Previous experiences with death/loss.
  - c. Children's responses.
  - d. Other stresses in family.
  - e. Maternal and infant medical history.
  - f. Pregnancy and birth history.
  - g. Life with infant including history of day of death.
  - h. Interaction experiences with first responder, coroner, etc.
  - i. Cultural practices related to death/dying, grief/grieving.
8. The PHN validates the assessment data with the family/ caregiver.
9. Documentation of the assessment is consistent with agency format.

## **STANDARD II. DIAGNOSIS**

***The Public Health Nurse analyzes the assessment data in determining nursing diagnoses.***

### *Measurement Criteria*

1. The family/caregiver responses to a death from SIDS are derived from the assessment data.
2. The family/caregiver responses are validated with them, significant others, and healthcare providers, when possible.
3. The family/caregiver responses are documented in a manner that facilitates the determination of expected outcomes and plan of care.

## **STANDARD III. OUTCOME IDENTIFICATION**

***The Public Health Nurse identifies expected outcomes individualized to the family/caregiver.***

### *Measurement Criteria*

1. The family/caregiver is contacted within three (3) working days of the Health Department receiving notice of the death from the coroner or other reporting agency.
2. The outcomes are mutually identified and formulated with the family/caregiver and other health care providers, when possible.



3. Documentation of services provided is complete and recorded in accordance with local and state protocols.
4. The family/caregiver has an increased knowledge and demonstrates an understanding of SIDS.
5. The family/caregiver has had their questions and concerns regarding SIDS addressed.
6. The family/caregiver is progressing through the grieving process, including resolution of self blame, if appropriate.
7. The family/caregiver has received information on local resources and services and appropriate SIDS information.
8. The family/caregiver is able to make informed decisions about available services.
9. The family/caregiver has been given the option of further follow-up.

## STANDARD IV. PLANNING

***The Public Health Nurse develops a plan of care that prescribes interventions to assist the families/caregivers and identifies expected outcomes.***

### *Measurement Criteria*

1. A nursing care plan, including follow-up, is developed in conjunction with the family/caregiver.
2. The nursing care plan includes the provision of information, support, referral and follow-up services within three (3) working days of receiving notice from the coroner or other reporting agency.
3. The nursing care plan is developed with specific measurable goals, intervention, and follow-up unique to the needs of the family/caregiver. The nursing care plan includes the following:
  - a. Prioritizes needs.
  - b. Stresses mutual goals developed with the family/caregiver.
  - c. Refers the family/caregiver to appropriate local resources and services.
  - d. Provides direction for continuity of care.
  - e. Includes a time frame for attainment of expected outcomes.
4. The nursing care plan for the family/caregiver reflects interdisciplinary and interagency collaboration.

## STANDARD V. IMPLEMENTATION

***The Public Health Nurse implements the interventions identified in the nursing care plan by providing case management services.***

### *Measurement Criteria*

1. Case management services provided include assessment, advocacy, intervention, monitoring, coordination of services, referral and follow-up to families/caregivers, foster parents and/or child care providers affected by a SIDS death.
2. Needed resources identified in the nursing care plan are available and accessible to all affected persons.
3. Family-centered care to families/caregivers is provided using a holistic approach.
4. The interventions are provided in a caring, listening, non-judgmental manner and combines SIDS knowledge, crisis intervention and grief counseling skills, and compassion to assist all individuals and family members who have experienced a loss from a SIDS death.
5. Interventions are performed in a culturally sensitive manner following the appropriate policies, procedures, administrative guidelines, and standards of practice.
6. Therapeutic interventions are provided in a supportive environment and are designed to reduce or manage stress and facilitate coping, and encourages the family/caregiver to express feelings.

7. Mechanisms exist within the agency for the professional to make timely interventions for both families and caregivers.
8. The infant's physician of record is notified of PHN contact if possible. This notification may include:
  - a. Informing physician of the infant's death.
  - b. Obtaining pertinent medical information.
  - c. Informing physician of PHN intervention plans.
  - d. Supplying physician with updated SIDS information and materials if needed.
  - e. Collaborating and coordinating services to the family.
9. Interventions are consistently documented using agency format.
10. There is access to the home and/or care setting.
11. Misconceptions family members/caregivers may have about circumstances surrounding the death, and about the cause of death are clarified and addressed.
12. The wide range of normal grief reactions is explained and discussed, and anticipatory guidance is provided.
13. The family/caregiver is assisted to recognize, understand and intervene as necessary with the grief reactions of surviving children.
14. The family/caregiver is encouraged to accept help from extended family, friends, SIDS peer contacts and professionals as necessary.



15. The family/caregiver is provided with resources including: SIDS peer contacts, professional counselors, and SIDS information to help with the grief process.
16. Arrangements for follow-up services are made as necessary.

## STANDARD VI. EVALUATION

***The Public Health Nurse evaluates the family/caregivers' progress toward attainment of expected outcomes.***

### *Measurement Criteria*

1. The nursing care plan is monitored to ensure the quality, timeliness, and effectiveness of services, modifying if appropriate.
2. Systems of accountability for outcomes of case management are established to ensure the well being of the family/caregiver.
3. The family/caregiver responses to interventions are documented.
4. Ongoing assessment data are used to revise nursing diagnosis, expected outcomes, and the nursing care plan, as needed.
5. Revisions in nursing diagnosis, expected outcomes, and the nursing care plan are documented.
6. The written evaluation documents consistency with agency standards for the home visit, applicable nursing practice, and confidentiality laws.

## STANDARDS OF PROFESSIONAL PERFORMANCE

### STANDARD I. QUALITY OF CARE

***The Public Health Nurse systematically evaluates the quality and effectiveness of nursing practice in the care of families/caregivers affected by a death from Sudden Infant Death Syndrome.***

#### *Measurement Criteria*

1. The PHN participates in quality assurance activities pertinent to the care of the family/caregiver as appropriate to the individual's position, and practice environment. Such activities to the family/caregiver may include:
  - Identification of indicators used to monitor quality and effectiveness of nursing care.
  - Collection of data to monitor quality and effectiveness of nursing care.
  - Analysis of quality data to identify opportunities for improving care.
  - Participation on interdisciplinary teams that evaluate clinical practice or services.
  - Development of policies and procedures to improve the quality of care.



2. The PHN uses the results of quality assurance activities to initiate changes in the delivery of care to the family/caregiver.
3. The PHN uses the results of quality assurance activities to initiate changes throughout the health care delivery system for the care of the family/caregiver, as appropriate.

## STANDARD II. PERFORMANCE APPRAISAL

***The Public Health Nurse evaluates his/her own nursing practice in the care of the family/caregiver affected by a death from Sudden Infant Death Syndrome in relation to professional practice standards and relevant statutes and regulations.***

### *Measurement Criteria*

1. The PHN engages in performance appraisal on a regular basis, identifying areas of strength as well as areas for professional practice development, including awareness of his/her own feelings about death and dying and focusing on the needs of the family/caregiver rather than one's own needs.
2. The PHN seeks constructive feedback regarding his/her own practice in the care of the family/caregiver affected by a death from SIDS.
3. The PHN takes action to achieve goals identified during performance appraisal related to the care of the family/ caregiver affected by a death from SIDS.
4. The PHN participates in peer review as appropriately related to the care of the family/caregiver affected by a death from SIDS.

### STANDARD III. EDUCATION

***The Public Health Nurse acquires and maintains current knowledge in nursing practice including the care of families/caregivers affected by a death from Sudden Infant Death Syndrome, current literature, and community resources.***

#### *Measurement Criteria*

1. The PHN participates in ongoing educational activities designed to maintain and increase his/her knowledge of the facts about SIDS and working with the family/caregiver affected by a death from SIDS, including the current status of research, understanding of the normal grief process, understanding of socio-cultural and individual differences in expression of grief, ethical issues, and referral resources in the community.
2. The PHN seeks knowledge and skills to maintain and improve nursing services when working with a family/caregiver affected by a death from SIDS, including assessment, case management, crises intervention, grief counseling, and referral and follow-up.



## STANDARD IV. COLLEGIALLY

***The Public Health Nurse contributes to the professional development of peers, colleagues, and others about the care of families/caregivers affected by a death from Sudden Infant Death.***

### *Measurement Criteria*

1. PHNs participate in community organizations concerned with SIDS and infant/child health such as: infant/child death review teams, child care agencies, and parent support organizations.
2. The PHN shares knowledge and skills about the care of a family/caregiver affected by a death from SIDS with colleagues and others.
3. The PHN provides peers with constructive feedback regarding their practice in working with the family/caregiver affected by a death from SIDS.
4. The PHN contributes to an environment that is conducive to the professional education of nursing students about the care of families/caregivers affected by a death from SIDS, as appropriate.

## STANDARD V. ETHICS

***The Public Health Nurse's decisions and actions on behalf of families/caregivers are determined in an ethical manner.***

### *Measurement Criteria*

1. The PHNs practice is guided by the Code for Nurses (2).
2. The PHN maintains confidentiality.
3. The PHN acts as a patient advocate.
4. The PHN delivers care in a nonjudgmental and nondisciplinary manner including sensitivity to cultural diversity and spiritual beliefs.
5. The PHN delivers care in a manner that preserves and protects the family/caregiver's autonomy, dignity, and rights.
6. The PHN seeks available resources to assist the family/caregiver to formulate their own ethical decisions.



## STANDARDS VI. COLLABORATION

***The Public Health Nurse collaborates with the families/caregivers affected by a death from Sudden Infant Death Syndrome, significant others, health care providers, and other agencies in providing care.***

### *Measurement Criteria*

1. The PHN communicates with the family/caregiver, significant others, health care providers, and other community resources and agencies regarding care, and the nurse's role in the provision of care.
2. The PHN consults with health care providers for the family/caregiver, as needed.
3. The PHN collaborates with community agencies to provide services.
4. The PHN interfaces with SIDS parent groups and peer contacts in the community.
5. The PHN provides consultation to agencies interacting with the family/caregiver affected by SIDS.
6. The PHN provides education (formal or informal) for individuals or agencies interacting with the family/caregiver.
7. The PHN makes referrals, including provision for continuity of care, as needed.

8. The PHN participates in the development of community resources.
9. The PHN participates in the assessment of community systems to identify problems.
10. The PHN collaborates with other disciplines in the evaluation of the service delivery system's responsiveness to the needs of the family/caregiver.
11. The PHN disseminates new SIDS information and research findings to interdisciplinary team members.
12. The PHN obtains personal support when necessary.

## STANDARD VII. RESEARCH

***The Public Health Nurse incorporates research findings into Public Health Nurse practice in the care of families/caregivers affected by a death from Sudden Infant Death Syndrome.***

### *Measurement Criteria*

1. The PHN uses interventions substantiated by research as appropriate.
2. The PHN participates in research activities related to the care of the family/caregiver affected by a death from SIDS as appropriate to the individual's position and practice environment. Such activities may include:
  - Identification of nursing problems in the care of families/caregivers.
  - Participation in data collection.
  - Participation in community research or programs related to SIDS.
  - Conducting research related to SIDS.
  - Utilization of research findings related to SIDS in the development of policies, procedures, and guidelines for care.

## STANDARD VIII. RESOURCE UTILIZATION

***The Public Health Nurse considers factors related to safety, effectiveness, and cost in planning and delivering care to the family/caregiver affected by a death from Sudden Infant Death Syndrome.***

### *Measurement Criteria*

1. The PHN evaluates factors related to the safety, effectiveness, and cost when two or more practice options would result in the same expected outcome for the family/caregiver.
2. The PHN assigns tasks or delegates care based on the needs of the family/caregiver and the knowledge and skill of the provider chosen.
3. The PHN assists the family/caregiver and significant others in identifying and securing appropriate services to address their identified needs.



## REFERENCES

1. American Nurses Association. 1991. *Standards of Clinical Practice*. Washington, D.C.: American Nurses Publishing.
2. American Nurses Association. 1985. *Code for Nurses with Interpretative Statements*. Washington, D.C.: American Nurses Association.

## COMMITTEE MEMBERS

**Gwen Barry**, P.H.N., M.P.H.  
California Association of Public Health Nurses

**Marilyn Chow**, D.N.Sc., R.N., F.A.A.N.  
American Nurses Association

**Betty Cofield**, P.H.N., M.P.H.  
Los Angeles County Department of Health Services

**Margo Derry**, P.H.N.  
Los Angeles County Department of Health Services

**Gwen Edelstein**, P.H.N., C.P.N.P., M.P.A.  
California Sudden Infant Death Syndrome Program

**Charleen Gorrell**, P.H.N., M.S.N.  
California Department of Health Services

**Kathleen Jarvis**, R.N., Ph.D.  
California State University, Sacramento

**Linda Levisen**, P.H.N.  
San Bernardino County Health Department

**Marcia Noonan**, P.H.N.  
California Sudden Infant Death Syndrome Program



**Kathy Sawyer, P.H.N.**  
Riverside County Health Department

**Penny Stastny, P.H.N.**  
Orange County Health Care Agency

**Mary Vernon, P.H.N.**  
California Association of Public Health Nurses

**Lucinda Wasson, P.H.N.**  
Kern County Health Department

**Judy Williams, P.H.N., M.S.N.**  
Santa Clara County Health Department

**James G. Winters, R.N., B.S.N., R.S., Ed.**  
California Department of Health Services

**Edited by:**

Gwen Edelstein,  
P.H.N., C.P.N.P., M.P.A.  
California SIDS Program

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Jay Gavron

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