

PROVIDING HOSPICE CARE TO RESIDENTS  
OF INTERMEDIATE CARE FACILITIES FOR THE  
DEVELOPMENTALLY DISABLED



CALIFORNIA COALITION  
*for* COMPASSIONATE CARE

Spring 2008

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## Acknowledgements

Thank you to the California Coalition for Compassionate Care's Developmental Disabilities Workgroup. Your input and guidance was invaluable.

This guide was prepared by the California Coalition for Compassionate Care and Susan Poor, MPH of Susan Poor Consulting.

# Providing Hospice Care to Residents of Intermediate Care Facilities For the Developmentally Disabled

## Introduction

In 2004, several organizations contacted the California Coalition for Compassionate Care (CCCC) for assistance with determining whether hospice can be provided in Intermediate Care Facilities for the Developmentally Disabled (ICF/DDs). As CCCC explored this issue, it became clear that broad confusion existed among providers and regulators about the legal requirements that govern the provision of such care.

To resolve these questions, CCCC formed a Workgroup on Developmental Disabilities. Over the past few years, the Workgroup has studied end-of-life issues for the developmentally disabled population and has made great strides in helping increase interest in this issue. In the course of its work, the Developmental Disabilities Workgroup determined that a guide regarding hospice in ICF/DDs would be useful.

This guide is designed to facilitate access to hospice services by persons who live in ICF/DDs. It outlines some of the regulatory requirements that apply when hospice is provided in ICF/DDs, and it is intended to help ICF/DD administrators and staff, hospice providers, Licensing and Certification staff, Medi-Cal staff, Regional Centers, and others who are involved with hospice care in an ICF/DD.

To gather information for this guide, CCCC compiled and analyzed existing laws, regulations, and guidelines related to both hospice care and care provided in ICF/DDs. In addition, key representatives of the California Department of Developmental Services, the California Department of Public Health, Regional Centers, hospices, ICF/DDs, California Department of Healthcare Services, the California Association of Health Facilities, and the California Hospice and Palliative Care Association were interviewed.

## Background

### About Developmental Disabilities

A “developmental disability” is a condition that originates before an individual reaches age 18, continues – or can be expected to continue – indefinitely, and constitutes a substantial impairment in three or more areas of major life activity. Developmental disabilities include mental retardation, epilepsy, cerebral palsy, autism, and disabling conditions closely related to mental retardation or requiring treatment similar to that required by people with mental retardation. Developmental disability does not include other conditions that are solely attributable to a psychiatric, physical, or learning disability.<sup>1</sup>

The Lanterman Developmental Services Act, passed by the California Legislature in 1969, defines the rights of people who have developmental disabilities, ensures that eligible individuals will receive appropriate services, and defines how those services will be delivered. This law ensures the coordination and provision of services and supports to enable people with developmental disabilities to lead more independent, productive, and integrated lives. With respect to community services, the Act provides for the establishment of the Regional Center network to provide fixed points of contact for individuals and their families throughout their lifetimes.<sup>2</sup>

The California Department of Developmental Services (DDS) is responsible for administering the Lanterman Act, carrying out its responsibilities through 21 community-based, not-for-profit Regional Centers, five State Developmental Centers, and two small state-run facilities. The service delivery system offers personalized supports and includes individuals with developmental disabilities, their families and/or legal representatives,

advocacy and professional organizations, the State Council on Developmental Disabilities, direct service providers, the state-run facilities, the Regional Centers, and DDS.<sup>3</sup>

The Lanterman Act's policy directive is to provide "opportunities for individuals with developmental disabilities to be integrated into the mainstream of life in their home communities, including supported living and other appropriate community living arrangements."<sup>4</sup>

To this end, and buttressed by the 1999 Olmstead decision,<sup>5</sup> the number and proportion of developmentally disabled individuals served in community settings has increased steadily over the past 40 years, while the number of individuals in state facilities has decreased.<sup>6</sup> In December 2007, DDS served about 192,000 individuals in community settings, compared to 155,000 in 1995.<sup>7</sup> Of the 192,000 individuals in community settings, about 74% (142,000) live with their families, while an additional 22% (42,000) live in community care or independent/supportive living settings and about 4% (7,700) live in ICF/DDs<sup>8</sup>

### About Intermediate Care Facilities

ICFs are health facilities licensed by the Licensing and Certification Division of the California Department of Public Health to provide 24-hour-per-day services. There are four types of ICFs providing services for Californians with developmental disabilities who reside in the community<sup>9</sup>:

- **ICF/DD** facilities have 16 or more beds. Residents may have intermittent or continuous needs for nursing care. There are approximately 20 of these facilities in California.
- **ICF/DD-H (Habilitative)** facilities have 15 beds or less and whose residents usually have intermittent needs for nursing care. The term "habilitative" means services are provided for the purpose of enhancing or preventing regression of intellect, functional skills and the emotional well-being of the person. Typically, care is provided in a group home setting. More than 85% of California's 700-plus ICF/DD-H facilities contain six or fewer beds.
- **ICF/DD-N (Nursing)** facilities have 15 beds or less and serve people with continuous needs for nursing care to monitor medications or conditions such as epilepsy. More than 90% of ICF/DD-N clients use wheelchairs. There are approximately 240 ICF/DD-Ns in California.
- **ICF/DD-CN (Continuous Nursing) Pilot Program** facilities provide services similar to ICF/DD-N services, with the addition of 24-hour skilled nursing services (licensed vocational nurses and registered nurses) for those whose medical conditions require continuous nursing care and observation. The ICF/DD-CN facilities provide these services for 4-15 consumers in a community-based living arrangement, with preference given to facilities serving 4-6 individuals. The pilot project is currently limited to selected participants, and no new facilities are currently being developed.

ICF/DDs are paid on a per diem basis. The per diem rate varies based on the number of beds in the facility.

### About Hospice Care

Hospice offers services specifically designed for the needs of the terminally-ill and their caregivers/families. Patients may receive care in their home, in skilled nursing facilities and ICF/DDs, at residential care facilities, or in local hospitals. Hospice care is designed to honor a person's wishes and values during the final stages of life, while responding to the person's physical, emotional, and spiritual needs. Services include nursing care, home health aides, counseling and social services, spiritual support, respite care and the support of trained volunteers. Grief and bereavement support is available to family members following a person's death and, more broadly, to anyone in the community who has suffered the loss of a loved one.

Hospice care is covered by Medicare, Medi-Cal and most private insurance. The Medicare and Medi-Cal hospice benefits are available for two periods of 90 days and an unlimited number of 60-day periods, provided that certain medical criteria continue to be met and the patient still desires hospice care. Patients may enroll in

hospice as soon as their physician and the hospice medical director determine that the illness is terminal, with an estimated life-expectancy of six months or less.

Hospice is paid on a per diem basis for the services it provides. Hospices receive four different rates – for routine home care, continuous home care, inpatient respite care, and general inpatient care. The basic rate for routine home care in federal fiscal year 2008 is \$135.11/day, though the rate may vary based on the location of the hospice.<sup>10</sup> (See Attachment K.)

## Hospice in ICF/DDs

### Providing Hospice Care in ICF/DDs

Residents of ICF/DDs may receive hospice services in an ICF/DD.<sup>11</sup> (See Attachment H.) ICF/DD residents are not required to be transferred to a higher level of health facility, such as a skilled nursing facility, in order to receive hospice services. They may continue to reside in the ICF/DD as long as the individual's care needs are adequately met consistent with their wishes as expressed or their best interest.

### Informed Consent & Capacity

The California Department of Health Services has issued a bulletin on informed consent requirements for individuals in ICFs. The bulletin provides information about assessing the capacity of adults in California ICFs to give informed consent for health treatments, describes California laws that allow for “legally authorized” representation for adults who lack capacity to give informed consent for “health care,” and provides information about the rights of individuals living in ICFs to be informed of their treatment options.<sup>12</sup> (See Attachment F and G.)

The information that follows is based on recommendations issued by the California Department on Public Health, and can be used as a reference for the licensing and certification issues related to hospice in the areas of outside services, client rights, health and safety and active treatment. This information is consistent with state and federal requirements if properly implemented.<sup>13</sup> (See Attachments D & E.)

### Funding

It is important to note that before a patient starts hospice services, reimbursement negotiations between the hospice and the ICF/DD facility should be completed.

Hospice care may be funded through various means:

- Medi-Cal, if the patient is a Medi-Cal beneficiary
- Medicare
- Regional Center
- Private pay arrangements
- Private health care insurance

The hospice benefit is usually paid to a single provider. In most cases, this means the hospice benefit will be paid directly to the hospice providing the service; the hospice would then reimburse board and care fees to the ICF/DD.

The ICF/DD per diem is set at 95% of normal costs because there is an assumption that hospice involvement assists the ICF/DD in providing and managing the patient's care. If the contractual agreement between the hospice and ICF/DD states that the ICF/DD will provide specific care or services normally provided by hospice, then hospice can pay the ICF/DD 100% of the per diem rate, if it is so stated in the contract.

## Billing

State and federal resources for billing for hospice care include the following:

1. For California, the hospice section of the Medi-Cal provider manual provides information on billing policies and instructions (available at [http://files.medi-cal.ca.gov/pubsdoco/io\\_manual.asp](http://files.medi-cal.ca.gov/pubsdoco/io_manual.asp)).
2. Medicare and Medi-Cal regulations are available at the websites provided below:
  - a) Federal regulations regarding Hospice as a Medicare Part A benefit are found in Title 42, California Code of Federal Regulations (CFR), Part 418, <http://www.gpoaccess.gov/cfr>.
  - b) State regulations regarding Hospice as a Medi-Cal benefit are found in Title 22, California Code of Regulations, Sections 51180, 51250, 51349 and 51544, <http://government.westlaw.com/linkedslice/default.asp?SP=CCR-1000>.

## Services

A hospice and an ICF/DD, ICF/DD-H or ICF/DD-N that are providing services jointly to a patient must develop a written contract before hospice services start. Both hospice and the ICF should include key managerial staff in contract and procedural negotiations.

The contract should address the following issues:

- Client eligibility, desire for, and choice of hospice services.
- Client rights and confidentiality.
- Orientation and continuing education of staff caring for the client.
- Hospice staff access to and communication with facility staff, and development of a coordinated plan of care.
- Documentation of changes in client's condition and appropriate palliative care provided to respond to the decline in the client's condition, consistent with the client's wishes or best interest and the individual plan of care.
- Documentation of services provided in each agency's clinical records that ensures continuity of communication and easy access to information.
- Role of hospice vendors in delivering supplies and medications.
- Ordering, renewal, delivery, administration, and management of medications, and destruction of unused medications.
- Role of the attending physician and processes for obtaining and implementing physician orders, as well as reviewing/discontinuing physician orders no longer required, as evidenced by the client's condition.
- Communicating the client's change of condition.

The ICF/DD will need to revise the active treatment plans and goals to accommodate the dual roles of the facility and hospice in providing palliative care. Active treatment programs should reflect the level of functioning and the wishes of the individual patient. The Center for Medicare and Medicaid Services (CMS) has stated that hospice care is active treatment if delivered in accordance with federal regulations.<sup>14</sup> (See Attachment H.)

The Comprehensive Functional Assessment (CFA) and the Individual Program Plan (IPP) must be updated when a resident elects the hospice benefit, and as the client's needs change.

The ICF/DD must notify the hospice agency as soon as possible when the resident experiences a change of condition. Specific procedures for notification should be addressed in the contract and the coordinated plan of care. The ICF/DD must also inform hospice when new staff is hired and facilitate their orientation by hospice staff.

## Coordination of Care Practices

Hospice and the ICF/DD must provide on-going training to staff about hospice philosophy, regulatory requirements and implementation of the residents' coordinated plan of care. ICF/DD direct care staff must be trained by hospice before hospice services begin.

The coordinated plan of care should identify the discipline and provider responsible and accountable for each intervention. The plan should also identify all services necessary to meet the needs of the resident and family including:

- psychosocial,
- medical, and
- spiritual needs.

ICF/DD and hospice staff must maintain open communication about clients' needs, with input from their families and/or authorized representatives. The ICF/DD, regional center and hospice must develop and agree upon a coordinated plan of care that is based on the individuals' needs, the unique living arrangement in the ICF/DD and relevant requirements and regulations.

The ICF/DD and hospice may continue to use their individual forms for care planning. However, both forms must reflect the resident's current identified health concerns, complimentary interventions and consistent palliative goals. The ICF/DD and hospice must develop a process to exchange information when developing and evaluating outcomes and revising the plan of care. Hospice and ICF/DD staff must actively seek input from the residents and/or their representatives regarding their desired goals.

If the hospice plan of care exceeds the ICF/DD plan of care for a resident, the additional services must be provided by hospice.<sup>15</sup> For example, if the hospice nurse feels that the resident needs more frequent bathing than the ICF/DD plan of care calls for, the additional services must be provided by a hospice home health aide.

## Pain & Comfort Assessment

The coordinated plan of care should describe the responsibilities of both the ICF/DD and hospice regarding assessment and management of pain and discomfort.

If pain management is an identified need, procedures must be put in place to ensure that the resident receives medications and treatments in a timely manner for optimal palliation. Hospice staff should educate ICF/DD staff regarding the resident's pain management regime, and coordinate with ICF/DD staff to monitor effectiveness of pain and symptom control treatments.

## Regulatory Requirements

Regulatory requirements are specific for each provider – ICF/DD and hospice. Each needs to be knowledgeable about basic regulations regarding the other. ICF/DD and hospice should share information with each other about applicable regulations and provide on-going training as needed.

The goal of coordination of care for the ICF/DD and hospice is to ensure adequate care for residents as their conditions decline and needs change. Hospice care must support the ICF/DD requirements for residents' rights and active treatment,<sup>16</sup> which means that the client is enabled to maintain maximum function within the limits of the disease process.

The ICF/DD must protect the well being, rights and quality of life for residents of the facility. In addition, the ICF/DD and hospice should work together to support the staff and housemates of the dying resident throughout the dying process.

## Conclusion

Neither the hospice nor ICF/DD system of care was developed with the other in mind. While they have in many things common – including an interdisciplinary team approach to care, a commitment to respecting the end-of-life decision-making process, and a focus on vulnerable clients – their true effectiveness as partners in care will come as they work together and better understand the work of the other. With hospice’s expertise in end-of-life care and the expertise of the ICF/DD in caring for the developmentally disabled, collaborative efforts between the organizations have the potential to provide the “best of both worlds” to members of the developmentally disabled community.

It is our hope that this guide will help promote and support this process.

## Endnotes

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<sup>1</sup> Department of Developmental Services, *Fact Book – 9<sup>th</sup> Edition*, June 2007; Department of Developmental Services, *Program Plan Information and Development*, ICF/DD-H, January 1, 2008.

<sup>2</sup> Ibid.

<sup>3</sup> Ibid.

<sup>4</sup> Department of Developmental Services, *Fact Book – 9<sup>th</sup> Edition*, June 2007.

<sup>5</sup> The Olmstead Decision, issued by the Supreme Court in 1999, required states to “place persons with mental disabilities in community settings rather than in institutions when the State’s treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated ...”

<sup>6</sup> When the Lanterman Act was passed in 1969, 13,500 people with mental retardation lived in four overcrowded state hospitals. (Source: *History of the Developmental Disabilities Service Delivery System in California*, Association of Regional Center Agencies). Today, about 2,700 developmentally disabled individuals live in seven state facilities. (Source: Department of Developmental Services, *Monthly Consumer Caseload Report*, through December 2007).

<sup>7</sup> Department of Developmental Services, *Monthly Consumer Caseload Reports*. The figures reported here do not include children served by the California Early Intervention Services Act.

<sup>8</sup> These figures are derived from data in the Department of Developmental Services, *Fact Book – 9<sup>th</sup> Edition*, June 2007. The DDS website at <http://www.dds.cahwnet.gov/DDSHomePage.cfm> has additional information about the different types of community living settings for developmentally disabled individuals. The *Fact Book* is also available on the DDS website.

<sup>9</sup> California Association of Health Facilities, *Glossary*, <http://www.cahf.org/public/dsc/glossary.php>; Department of Developmental Disabilities Website, <http://www.dds.cahwnet.gov/icf/ICF.cfm>; Department of Developmental Services, *Program Plan Information and Development*, ICF/DD-H, January 1, 2008.

<sup>10</sup> Centers for Medicaid and Medicare Services, *Hospice Payment Systems*, December 2007. (Attachment A.)

<sup>11</sup> Letter to Judy Citko from Diane Smith, CMS – ICF/MR, October 9, 2007. “Hospice Services, provided they meet the criteria found at 42CFR418.1 – 418.405 Subparts A – H and the Social Security Act 1861 (dd), are allowable and appropriate for people living in an ICF/MR and are considered to be their active treatment program. The ICF/MR regulations have never precluded Hospice Services for individuals since active treatment is predicated on identifying the individual’s needs and meeting those needs.” (Attachment B.)

<sup>12</sup> Informed Consent Requirements for Individuals in Intermediate Care Facilities, DHS Licensing and Certification Informed Consent Bulletin, August 2003. Information Related to Informed Consent, Department of Health Services (DHS) AFL 03-23, August 1, 2003. (Attachments C and D.)

<sup>13</sup> California Department of Public Health, “Recommendations for Hospice Services for the ICF/DD, ICF/DD-H and ICF/DD-N Facility, All Facilities Letter 07-27, September 27, 2007. (Attachment E) Additional information about this AFL can be found in “Hospice in ICF,” presentation by Elaine Rawes RN, California Department of Public Health, Licensing & Certification-Special Projects, explaining All Facilities Letter 07-27, October 2007. (Attachment F)

<sup>14</sup> Letter to Judy Citko from Diane Smith, op cit. Active Treatment Statement, October 9, 2007

<sup>15</sup> Phone conversation with Margaret Clausen, President/CEO, California Hospice and Palliative Care Organization, January 23, 2008.

<sup>16</sup> Letter to Judy Citko from Diane Smith, op cit.

## Information Sources

### Websites

- Association of Regional Center Agencies, [www.arcenet.org](http://www.arcenet.org)
- California Association of Health Facilities, <http://www.cahf.org>
- California Department of Developmental Services, <http://www.dds.cahwnet.gov>
- Centers for Medicare & Medicaid Services, Intermediate Care Facilities for the Mentally Retarded (ICFs/MR), [http://www.cms.hhs.gov/CertificationandCompliance/09\\_ICFMRs.asp](http://www.cms.hhs.gov/CertificationandCompliance/09_ICFMRs.asp)
- Developmental Disabilities Resources for Healthcare Providers, [www.ddhealthinfo.org](http://www.ddhealthinfo.org)

### Documents

- Active Treatment Statement, Centers for Medicare & Medicaid Services, October 9, 2007
- Do Not Resuscitate (DNR) Information Sheet for Intermediate Care Facilities/Developmentally Disabled - Habilitative or Nursing, Compiled by Elaine Rawes RN, California Department of Health Services Licensing & Certification Program, 2007
- Fact Book – 9th Edition, California Department of Developmental Services, June 2007
- Glossary, California Association of Health Facilities, Developmental Services section of website, undated
- History of the Developmental Disabilities Service Delivery System in California, Association of Regional Center Agencies, undated
- Hospice in ICF: Presentation by Elaine Rawes, RN, California Department of Public Health, Licensing & Certification-Special Projects, explaining All Facilities Letter 07-27, October 2007
- Information Related to Informed Consent, All Facilities Letter 03-23, California Department of Health Services, August 1, 2003
- Informed Consent Requirements for Individuals in Intermediate Care Facilities, Department of Health Services Licensing & Certification Informed Consent Bulletin, August 2003
- Lanterman Developmental Disabilities Services Act and Related Laws, California Department of Developmental Services, January 2007
- Medicare Hospice Payment System, Medicare Learning Network, Centers for Medicare & Medicaid Services, December 2007
- Monthly Consumer Caseload Reports, California Department of Developmental Services
- Pre-Hospital Do Not Resuscitate Forms, AFL 05-24, California Department of Health Services, 6/15/05
- Program Plan Information and Development ICF/DD-H, California Department of Developmental Services, January 1, 2008
- Recommendations for Hospice Services for the ICF/DD, ICF/DD-H, and ICF/DD-N Facility, All Facilities Letter 07-27, California Department of Public Health, September 27, 2007
- Regional Center Budget and Demographic Information, Association of Regional Center Agencies, 2008

## **List of Attachments**

Attachment A:	CCCC Developmental Disability Workgroup Membership
Attachment B:	Intermediate Care Facility Program Types
Attachment C:	Criteria for ICF/DD Placement
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Attachment J:	Information on Pre-hospital Do Not Resuscitate Form
Attachment K:	Hospice Payment System CMS Fact Sheet

## ATTACHMENT A

### California Coalition for Compassionate Care Developmental Disability Workgroup

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**Tony Anderson, MA**  
The Arc of California

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The Good Shepherd Fund

**Bob Baldo**  
Association of Regional Centers Agencies

**Mary Cadogan, DrPH, RN, NP**  
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**Mark Starford**  
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**ATTACHMENT A**

**California Coalition for Compassionate Care  
Developmental Disability Workgroup**

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**Terry Wardinsky, MD**

Alta California Regional Center

**Rose Wesley**

Social Work Student

**Samuel Yang, MD**

California Department of Developmental Services

## ATTACHMENT B

### INTERMEDIATE CARE FACILITY PROGRAM TYPES (ICF/DD, ICF/DD-H, ICF/DD-N, ICF/DD-CN)

Intermediate Care Facilities (ICF) are health facilities licensed by the Licensing and Certification Division of the California Department of Public Health (CDPH) to provide 24-hour-per-day services. The four types of ICFs providing services for Californians with developmental disabilities in the community are:

#### **ICF/DD (Developmentally Disabled)**

"Intermediate care facility/developmentally disabled" is a facility that provides 24-hour personal care, habilitation, developmental, and supportive health services to developmentally disabled clients whose primary need is for developmental services and who have a recurring but intermittent need for skilled nursing services.

#### **ICF/DD-H (Habilitative)**

"Intermediate care facility/developmentally disabled-habilitative" is a facility with a capacity of 4 to 15 beds that provides 24-hour personal care, habilitation, developmental, and supportive health services to 15 or fewer developmentally disabled persons who have intermittent recurring needs for nursing services, but have been certified by a physician and surgeon as not requiring availability of continuous skilled nursing care.

#### **ICF/DD-N (Nursing)**

"Intermediate care facility/developmentally disabled-nursing" is a facility with a capacity of 4 to 15 beds that provides 24-hour personal care, developmental services, and nursing supervision for developmentally disabled persons who have intermittent recurring needs for skilled nursing care but have been certified by a physician and surgeon as not requiring continuous skilled nursing care. The facility shall serve medically fragile persons who have developmental disabilities or demonstrate significant developmental delay that may lead to a developmental disability if not treated.

#### **ICF/DD-CN (Continuous Nursing) Pilot Program**

These facilities provide services similar to ICF/DD-N services with the addition of 24-hour skilled nursing services (licensed vocational nurse and registered nurse) for those consumers whose medical conditions require continuous nursing care and observation. The ICF/DD-CN facilities provide these services for 4-15 consumers in a community-based living arrangement, with preference given to facilities serving 4-6 individuals. The pilot project is currently limited to selected participants and no new facilities are currently being developed.

Source: Health & Safety Code online: [www.leginfo.ca.gov](http://www.leginfo.ca.gov)  
DDS ICF/DD-H packet, Section II: ICF Program Types, 1/1/2008

## ATTACHMENT C

### CRITERIA FOR ICF/DD PLACEMENT

Note: Individuals being considered for ICF placement must be Regional Center clients.

#### Entrance Criteria for ICF/DD-H (Habilitative)

- Client has stable medical and nursing care needs, which do not require continuous skilled nursing services
- Client's predominant skilled nursing needs are predictable so that advance arrangement can be made to provide for needs.
- Client receives medication that requires professional or pharmacist nurse evaluation on an intermittent basis.
- Client must be between a specific age group determined by facility, i.e. 18-59 years old (this is flexible and more easily adjusted than in the CCL world)
- Client may be ambulatory or non-ambulatory
- Client will benefit from a specialized developmental, training and habilitative program as evidenced by:
  - a higher level of functioning
  - a lessening dependence on others in daily living activities
  - prevention of regression
  - Client will display two or more developmental deficits in either the self-care or social-emotional domain

#### Entrance criteria for ICF/DD-N (Nursing)

- Client has significant but stable medical and nursing care needs, which do not require continuous skilled nursing services
- Client's predominant skilled nursing needs are predictable so that advance arrangement can be made to provide for needs.
- Client receives medication that requires professional or pharmacist nurse evaluation on an intermittent basis.
- Client must be between a specific age group determined by facility, i.e. 18-59 years old
- Client may be ambulatory or non-ambulatory
- Client will benefit from a specialized developmental, training and habilitative program as evidenced by:
  - a higher level of functioning
  - a lessening dependence on others in daily living activities
  - prevention of regression
  - Client will display two or more developmental deficits in one or in combination of the following three domains: self-care domain, motor domain, social-emotional domain

#### Entrance criteria for ICF/DD-CN (Continuous Nursing)

- Need to be able to demonstrate the skilled intervention for each shift.
- Medically stable, but needing regular skilled interventions:
  - Tracheostomy, with or without ventilator
  - Special feeding needs

- Intravenous feeding/medications
- Frequent medical and or nursing interventions
- Respiratory therapy
- Wound stage 3
- Dialysis

Source: Golden Gate Regional Center



MARK B HORTON, MD, MSPH  
Director

State of California—Health and Human Services Agency  
California Department of Public Health



ARNOLD SCHWARZENEGGER  
Governor

**ATTACHMENT D**

September 27, 2007

AFL 07-27

**TO: ALL INTERMEDIATE CARE FACILITY/DEVELOPMENTALLY  
DISABLED (ICF/DD)  
ALL INTERMEDIATE CARE FACILITY/DEVELOPMENTALLY  
DISABLED-HABILITATIVE (ICF/DD-H)  
ALL INTERMEDIATE CARE FACILITY/DEVELOPMENTALLY  
DISABLED- NURSING (ICF/DD-N)**

**SUBJECT: RECOMMENDATIONS FOR HOSPICE SERVICES FOR THE ICF/DD,  
ICF/DD-H AND ICF/DD-N FACILITY**

The following is information designed to give providers and surveyors a greater understanding of ICF/DD, ICF/DD-H and ICF/DD-N facility types and hospice recommendations.

When an individual becomes terminally ill, difficult decisions have to be made as to whether or not the individual may continue to be cared for in their own home.

An individual who becomes terminally ill and lives in an ICF/DD, ICF/DD-H, or ICF/DD-N should not be required to be transferred out of that facility in order to comply with California Department of Public Health, Licensing & Certification requirements. A dignified death at home may be an *option* for individuals in ICF/DD, ICF/DD-H or ICF/DD-N facilities as long as the individual's care needs are adequately met consistent with their wishes as expressed, or their best interest.

The following recommendations are based on current law, regulations and community standards for ICF/DD, ICD/DD-H and ICF/DD-N providers who are considering working with a hospice agency to provide care to a terminally ill client in their home.

This information is offered as a reference for the licensing & certification issues related to hospice in the areas of outside services, client rights, health and safety, and active treatment, and are consistent with the state and federal requirements if properly implemented.

## **Funding**

Reimbursement negotiations should be completed prior to the initiation of hospice services in the ICF facility.

Hospice care may be funded through various resources:

- Medi-Cal, if the individual is a Medi-Cal beneficiary.
- Medicare.
- Regional Center.
- Private pay arrangements.
- Private health care insurance. (Benefits may be paid for up to one year)

It is generally understood that the Hospice benefit will be paid to a single provider. Therefore, under most circumstances, the Hospice benefit will be paid directly to the Hospice and the Hospice would then reimburse board and care fees to the provider.

## **Services**

A hospice agency and ICF/DD, ICF/DD-H or ICF/DD-N provider that is providing services jointly to an individual client must develop a written contract **prior** to the commencement of services. The contract should address the following issues:

- Client eligibility, desire for, and the choice of hospice services.
- Client rights and confidentiality.
- Orientation and continuing education of staff caring for the client.
- Hospice staff access to and communication with facility staff, and development of a coordinated plan of care.
- Documentation of changes in client's condition and appropriate palliative care provided to respond to the decline in the client's condition, consistent with the client's wishes or best interest and the individual plan of care.
- Documentation of services provided in each entities' clinical records that ensures continuity of communication and easy access to ongoing information.
- Role of any hospice vendor in delivering supplies and medications.
- Ordering, renewal, delivery, administration, and management of medications, and destruction of unused medications.
- Role of the attending physician and processes for obtaining and implementing physician orders, as well as reviewing/discontinuing physician orders no longer required, as evidenced by the client's condition.
- Communicating the client's change of condition.

The hospice agency and the ICF/DD, ICF/DD-H or ICF/DD-N administrative staff should share common philosophical values in end-of life care and the active treatment concept of maintaining function to the maximum extent possible in the face of a deteriorating condition.

The facility will be required to revise the active treatment plans and goals in order to simplify the dual roles of the facility and the hospice in the provision of palliative care, and in the identification of needed supports for the effectiveness of the team approach. Active treatment programs may be as simple or as elaborate as the level of functioning of the individual client permits, and his/her receptiveness to the developed treatment program allows.

The Comprehensive Functional Assessment (CFA) and the Individual Program Plan (IPP) must be revised and updated when a client elects the hospice benefit, and also as the client's needs change. The ICF/DD, DD-H or DD-N must notify the hospice agency when the resident experiences a change of condition. The facility must continue to meet requirements for notifying the physician, family, and/or the client's representatives of a change in condition. The procedures for notification may be addressed in the coordinated plan of care. The facility must inform the hospice agency of new facility staff and facilitate staff's orientation by the hospice.

### **Coordination of Care Practices**

The hospice agency and ICF/DD, DD-H or DD-N facility must provide on-going training to applicable staff, as needed, regarding the hospice philosophy, the ICF/DD, DD-H and DD-N regulatory requirements, and the implementation of the individuals' coordinated plan of care. Orientation and training information must be given to, and understood by, all direct care staff before hospice care is given to the clients.

Both the facility and the hospice should include key managerial staff in contract and procedural negotiations.

The ICF/DD, DD-H or DD-N facility provider and the hospice agency must open lines of communication centering on client's needs, with input from their families and/or authorized representatives.

The ICF/DD, DD-H or DD-N facility provider, the regional center, and the hospice agency must communicate, establish, and agree upon a **coordinated plan of care** that reflects a philosophy consistent with all requirements, and is based on an assessment of individuals' needs and the unique living arrangement in the ICF/DD, DD-H or DD-N facility.

The coordinated plan of care identifies all services necessary to meet the physical, psychosocial, medical, and spiritual needs of the client/family as reflected in the

coordinated plan of care, and identifies the discipline and provider to be held responsible and accountable for each intervention.

### **Assessment for Pain/Comfort**

The coordinated plan of care describes the responsibilities of each entity regarding the assessment and management of pain and discomfort.

If pain management is an identified need, procedures must be put in place to assure that the client receives timely medications and treatments for optimal palliation.

The hospice agency provides education to the ICF/DD, DD-H or DD-N facility staff on the client's pain management regime, and coordinates with the facility staff to monitor the effectiveness of the pain and symptom control treatments.

The ICF/DD, DD-H or DD-N facility and hospice may continue to utilize their individual forms for care planning. ICF/DD, DD-H or DD-N facilities client-centered and individual program plan and the hospice's individualized health care plans must reflect the client's current identified health concerns, complimentary interventions, and consistent palliative goals.

The ICF/DD, DD-H and DD-N and the hospice together must determine a process by which information from the hospice and facility interdisciplinary staff/team will be exchanged when developing and evaluating outcomes and revising the plan of care. The team must actively seek input from the clients and/or their representatives on desired goals.

### **Regulatory Requirements**

The regulatory requirements are specific for each provider. Both providers should be knowledgeable of the basic requirements of the other provider's regulatory requirements. Each provider should orient the other to its requirements, and may provide ongoing education to meet the needs of each.

The ICF/DD, DD-H or DD-N facility and hospice agency shall maintain compliance with all federal, state, and local laws and regulations.

The goal of coordination of care for the ICF/DD, DD-H or DD-N facility, in partnership with the hospice agency and regional center, is to ensure adequate care for clients as their conditions decline and needs change.

Hospice care must support the ICF/DD, DD-H or DD-N requirements for client's rights and active treatment, which means that the client is enabled to maintain maximum function within the limits of the disease process.

The ICF/DD, DD-H or DD-N must protect the well being, rights, and quality of life for all clients living in the facility. The facility and hospice agency must also work together to positively support the housemates of the dying client throughout the experience.

Should you have questions about this informative bulletin, please contact Elaine Rawes, RN of my staff at (916) 552-8750, or email her at [Elaine.Rawes@cdph.ca.gov](mailto:Elaine.Rawes@cdph.ca.gov).

Sincerely,

**Original Signed by Kathleen Billingsley, R.N.**

Kathleen Billingsley, R.N.  
Deputy Director  
Center for Healthcare Quality

# ATTACHMENT E

## Hospice in ICF

Presentation by Elaine Rawes RN, California Department of Public Health, Licensing & Certification-Special Projects, explaining All Facilities Letter 07-27 (Recommendations for Hospice Services for the ICF/DD, ICF/DD-H, and ICF/DD-N Facility)

When an individual becomes terminally ill, difficult decisions as to whether or not the individual may continue to be cared for in the facility, their own home need to be made.



A dignified death at home should be an *option* for individuals in ICF facilities. The individual's care needs must be met consistent with their wishes as expressed, or their best interest.



**Recommendations** are based on current law, regulations and community standards for ICF providers.



**Reference** for issues related to hospice in the areas of outside services (Home Health Agency/Hospice), client rights, health and safety, and active treatment.



**Reimbursement** negotiations should be completed **prior** to the initiation of hospice services in the ICF facility. Hospice care may be funded through various resources:

- Medi-Cal, if the individual is a Medi-Cal beneficiary.
- Medicare.
- Regional Center.
- Private pay arrangements.
- Private health care insurance. (Benefits may be paid for up to one year)

Hospice benefit will be paid to a single provider. Under most circumstances, the Hospice benefit will be paid directly to the Hospice and the Hospice would then reimburse board and care fees to the provider.



**Develop** a written contract **prior** to the commencement of services (Hospice agency and ICF provider jointly providing services to an individual client.)



- Client eligibility, desire for, and the choice of hospice services.
- Client rights and confidentiality.
- Orientation and continuing education of staff caring for the client.
- Hospice staff access to and communication with facility staff, and development of a coordinated plan of care.
- Documentation of changes in clients' condition and appropriate palliative care provided to respond to the decline in the client's condition, consistent with the clients' wishes or best interest and the individual plan of care.
- Documentation of services provided in each entity's clinical records that ensures continuity of communication and easy access to ongoing information.
- Role of any hospice vendor in delivering supplies and medications.
- Ordering, renewal, delivery, administration, and management of medications, and destruction of unused medications.
- Role of the attending physician and processes for obtaining and implementing physician orders, as well as reviewing/discontinuing physician orders no longer required, as evidenced by the clients' condition.
- Communicating the clients' change of condition.



Hospice agency and the ICF administrative staff should **share common philosophical values** in end-of life care and the active treatment concept of maintaining function to the maximum extent possible in the face of a deteriorating condition.



ICF is required to **revise the active treatment plans and goals** in order to simplify the dual roles of the facility and the hospice in the provision of palliative care, and in the identification of needed supports for the effectiveness of the team approach. Active treatment programs may be as simple or as elaborate as the level of functioning of the individual client permits, and his/her receptiveness to the developed treatment program allows.



The Comprehensive Functional Assessment (CFA) and the Individual Program Plan (IPP) must be **revised and updated** when a client elects the hospice benefit, and also as the clients' needs change. The ICF must notify the hospice agency when the client experiences a change of condition. The ICF must continue to meet requirements for notifying the physician, family, and/or the clients' representatives of a change in condition. The procedures for notification may be addressed in the coordinated plan of care.



Hospice agency and ICF must provide on-going training to applicable staff, as needed, regarding the hospice philosophy, the ICF regulatory requirements, and the implementation of the individuals' coordinated plan of care. Orientation and training information must be given to, and understood by, all direct care staff before hospice care is given to the clients. The facility must inform the Hospice of new facility staff and facilitate staff's orientation by the hospice. Both the facility and the hospice should include key managerial staff in contract and procedural negotiations. Each provider should orient the other to its requirements, and may provide ongoing education to meet the needs of each.



The ICF provider and the hospice agency must **open lines of communication** centering on clients' needs, with input from their families and/or authorized representatives.



The ICF provider, the Regional Center, and the Hospice agency must communicate, establish, and agree upon a **coordinated plan of care** that reflects a philosophy consistent with all requirements, and is based on an assessment of individuals' needs and the unique living arrangement in the ICF.

The coordinated plan of care must identify all services necessary to meet the **physical, psychosocial, medical, and spiritual** needs of the client/family and identifies the discipline and provider to be held responsible and accountable for each intervention.



The coordinated plan of care describes the **responsibilities** of each entity regarding the assessment and management of **pain and comfort**. If pain management is an identified need, procedures must be put in place to assure that the client receives timely medications and treatments for optimal palliation.

Hospice agency provides education to the ICF staff on the client's pain management regime, and coordinates with the facility staff to monitor the effectiveness of the pain and symptom control treatment.



ICF and Hospice may continue to **utilize their individual forms** for care planning. The ICF client-centered and individual program plan and the Hospice's individualized health care plan must **reflect** the client's current identified health concerns, complimentary interventions, and consistent palliative goals.

ICF and the Hospice together must **determine a process** by which information from the hospice and ICF interdisciplinary staff/team will be exchanged when developing and evaluating outcomes and revising the plan of care. The team must actively seek input from the client and/or their representative on desired goals.

**Regulatory requirements** are specific for each provider. Both providers should be knowledgeable of the basic requirements of the other provider's regulatory requirements.



ICF facility and Hospice agency shall maintain **compliance** with all federal, state, and local laws and regulations. The goal of coordination of care for the ICF, in partnership with the Hospice agency and Regional Center, is to ensure **adequate care for clients as their conditions decline and needs change**.

Hospice care must support the ICF requirements for **clients' rights and active treatment**, which means that the client is enabled to maintain maximum function within the limits of the disease process.

The ICF must protect the well being, rights, and quality of life for all clients living in the facility. The ICF and Hospice agency must also work together to positively **support** the housemates of the dying client throughout the experience.



## QUESTIONS





DIANA M. BONTÁ, R.N., Dr. P.H.  
Director

State of California—Health and Human Services Agency  
**Department of Health Services**



GRAY DAVIS  
Governor

**ATTACHMENT F**

August 1, 2003

AFL No. #03-23

TO: ALL INTERMEDIATE CARE FACILITY/DEVELOPMENTALLY DISABLED (ICF/DD)  
ALL INTERMEDIATE CARE FACILITY/DEVELOPMENTALLY DISABLED-HABILITATIVE (ICF/DD-H)  
ALL INTERMEDIATE CARE FACILITY/DEVELOPMENTALLY DISABLED – NURSING (ICF/DD-N)

SUBJECT: INFORMATION RELATED TO INFORMED CONSENT

Attached is information designed to give providers and surveyors a greater understanding of “informed consent” as it applies to people receiving services in Intermediate Care Facilities for the Mentally Retarded (ICF/MR). We understand that the Center for Medicare and Medicaid Services (CMS) is reviewing protections in the area of informed consent for unconserved adults with developmental disabilities, and will be issuing additional guidance in this area. We expect that the information included in the attached bulletin will be compatible with future federal guidance. If, however, there are differences, we will revise and reissue the bulletin at that time.

This bulletin identifies state laws applicable to informed consent for this population and describes actions a provider may take to be in better compliance with federal requirements in this area. It is educational in its intent, and does not establish new enforcement standards.

The following list highlights the key elements of this document. Please see the referenced pages for further discussion of these elements:

- Assessment – Individuals’ needs for representation should be assessed as part of the Comprehensive Functional Assessment (Pages 2, 3, 6, & 7).



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[www.consumerenergycenter.org/flex/index.html](http://www.consumerenergycenter.org/flex/index.html)

- Physician determination of capacity – This should be decision-specific, and may vary depending on the complexity of the decision and the level of risk involved (Pages 2 & 9). The inter-disciplinary team should have input into this determination (Pages 2, 6, & 7).
- Individual Program Plan –An individual's IPP should reflect their identified needs for representation, including needs for support, training, assistive devices, and/or surrogate decision-making (Pages 2, 3, & 8).
- Self-representation as the goal – Individuals should be supported and trained, to the fullest extent possible, to participate in the granting or withholding of consent (Pages 2 & 7).
- Legally sanctioned surrogate decision-maker – California law provides for a variety of arrangements for representation, including the use of closest available relative (Pages 3 - 5).
- Interagency responsibilities – The provider is responsible to proactively pursue representation for individuals with this identified need, by soliciting potential representatives both verbally and in writing. Providers should notify appropriate government agencies of this unmet need. Cases where no authorized representative can be found should be referred to the Clients' Rights Advocate for legal review (Pages 7 & 8).

Should you have questions about this bulletin, please contact Jocelyn Montgomery, RN, Department of Health Services, Licensing and Certification, at (916) 552-9365, or e-mail her at [jmontgo2@dhs.ca.gov](mailto:jmontgo2@dhs.ca.gov).

Sincerely,

*Original signed by*

Brenda G. Klutz  
Deputy Director  
Licensing and Certification Program

Attachment

## ATTACHMENT G

### DHS/Licensing and Certification Informed Consent Bulletin –August 2003

**SUBJECT: Informed consent requirements for individuals in Intermediate Care Facilities for the Mentally Retarded (ICF/MR)**

#### PURPOSE

1. Provide information about assessing the capacity of adults who live in ICF/MR facilities in the State of California to give informed consent for health and behavioral treatments.
2. Describe the California laws, which are applicable under the ICF/MR model, that allow for “legally authorized” representation for adults who lack capacity to give informed consent for health care. This includes the use of “closest available relative” as a consent option that was recently reviewed by The Centers for Medicare and Medicaid Services (CMS).
3. Provide information regarding positive practices and state-mandated protections affecting the rights of individuals living in California ICF/MR facilities to be informed of their treatment options.

#### BACKGROUND

Federal regulations for ICF/MR facilities state that providers must “**allow and encourage individual individuals to exercise their rights as individuals of the facility, and as citizens of the United States**” [42 CFR 483.420(a)(3)]. These rights include the right to be informed of their “**medical condition, developmental and behavioral status, attendant risks of treatment, and the right to refuse treatment**” [42 CFR 483.420 (a) (2)].

The “Interpretive Guidelines” under these regulations state that an individual is sufficiently informed when they are aware of:

- The proposed treatment, procedures to follow, and who will perform the treatment.
- The intended outcomes or benefits.
- The possible risks.
- The ramifications of refusing treatment and the alternatives.
- The voluntary nature of his or her consent.

Additionally, this guidance advises surveyors to confirm that for experimental, invasive, and potentially harmful treatments:

- The consent is time limited.
- The individual or their representative realizes that consent can be withdrawn at any time.
- The person who gave the consent is the legally appropriate party to do so.

#### ASSESSING CAPACITY

California law (Probate Code 4657) states that an adult (18 years or older) is presumed to have the **capacity** to make health care decisions, give or revoke an advance directive, and designate or disqualify a surrogate. **Capacity** is defined as a person’s ability to:

- Understand the nature and consequences of a decision,

- Make and communicate a decision, and
- Understand the significant benefits, risks, and alternatives of a proposed treatment (Probate Code 4609).

It is the position of the Department (Department of Health Services, Licensing and Certification), **that individuals living in ICF/MR facilities are to be given the support, education, and opportunity to participate in their own health care and treatment decisions to the fullest possible extent.** This means that every ICF/MR provider should have a comprehensive and on-going system of assessment, training, and supports that enables individuals to maximize their potential for choice and self-determination. This system should:

- For regional center individuals, include the services of the regional centers,
- Begin with the pre-admission assessment,
- Result in consent needs being identified and addressed in the individualized program plan (IPP),
- Ensure that individuals, who have been assessed as needing additional education and/or adaptive devices to enhance their participation, are provided with same so that they can be included as much as possible in the decision-making process,
- Protect the rights of adults who have the capacity, to give or withhold informed consent for themselves.

Ideally, all adults with developmental disabilities will be empowered to make their own treatment decisions when given the appropriate support and adaptations. However, it is recognized by the Department, that even when given the appropriate support, education, and equipment, some individuals will still lack the capacity to make some or all of their treatment decisions. These individuals need to have an “authorized representative” for treatment decisions that require informed consent.

In California, the **primary physician** makes the determination that a patient **lacks** capacity to make a health care decision (Probate Code 4658 & 4732). The physician makes this determination based on their clinical assessment and the input of the interdisciplinary team (IDT). This determination should be **decision-specific** rather than global, because some health care decisions are more complex than others, and, given enough time and support, some individuals may gain capacity to make an informed decision regarding some aspects of their care. For example, an individual who has developmental disabilities may be able to understand the risks and benefits and give their own consent for the relatively simple decision to have a tooth removed. But the same individual may lack capacity to understand the risks and alternatives to a more complex decision involving psychotropic medication, and so would need the assistance of a representative in consenting to that treatment.

For the consent process, decisions that involve a higher risk of harm require a greater understanding of the potential risks and benefits. When there is any question of the individual’s capacity to understand the implications of a treatment decision that involves a significant risk, it is appropriate to involve an authorized representative to ensure that the individual’s wishes and best interests are protected.

## **CALIFORNIA LAWS ADDRESSING INFORMED CONSENT**

When an individual lacks the capacity to understand and communicate a health care decision, and thereby to give informed consent, a legally authorized representative must do this for them. There are several ways under California law to fulfill the need for what is described in the California Code of Regulations, Title 22 (76015, 76802) as the “**authorized representative**” for residents of Intermediate Care Facilities for the Developmentally Disabled, Habilitative, and Nursing (ICF/DD, ICF/DD-H, ICF/DD-N).

Which arrangement is most appropriate for a specific person depends on many factors that should be explored during the assessment process such as:

- The individual’s wishes and needs for representation,

- Who is available to represent them,
- The complexity of the treatment decisions that are involved, and
- The presence of a previously appointed conservator or agent.

Once an individual is assessed as lacking capacity to make some or all health care decisions, this need should be identified and reflected in their IPP (W&I 4646). The regional center service coordinator is assigned the responsibility of implementing, overseeing, and monitoring the IPP [W&I 4647(a) & (b)] and, as a member of the IDT, can work with the ICF/MR provider to ensure this need is appropriately met.

Under California law, all of the following arrangements are potentially available to individuals of ICF/MR facilities. It is the position of the Department, that when an individual lacks the capacity to make a treatment decision for themselves, they should be provided with the representation that affords him or her the greatest autonomy while protecting their rights.

1. **Appointment of a Surrogate** (Probate Code section 4711 et seq.). An adult who has capacity may designate another adult (orally or in writing) as a surrogate to make health care decisions by personally informing the supervising health care provider. The designation must be promptly recorded in the health care record. Unless the individual specifies a shorter period, the surrogate designated is effective only during the course of treatment or illness or during the stay in the health care institution when the surrogate designation is made, or for 60 days, whichever period is shorter.
2. **Advance Health Care Directive** (Probate Code 4600-4805). A Power of Attorney for Health Care can be completed by an adult who has the capacity to do so. This method could be utilized for an individual who can communicate their wishes, and has the capacity to understand the implications of allowing a designated agent to sign consents on their behalf. An advance health care directive may also be an individual health care instruction that is a patient's written or oral directive concerning a health care decision for the patient.
3. **Closest Available Relative** [*Cobbs v. Grant*, 8 Cal.3d 229, 244 (1972) and *Barber v. Superior Court*, 147 Cal.App.3d 1006 (1983)]. In some circumstances, the "closest available relative" can give consent. This method is acceptable if the following conditions can be clearly established:
  - The "closest" available relative means a person who is close in terms of blood or marital ties, and has a caring relationship to the individual. It is a person who is aware of the individual's values and beliefs, and is available to make the needed decisions. It does not refer to physical proximity.
  - The closest available relative is clearly guided by the individual's expressed wishes, or if his or her wishes are unable to be determined, by their best interests.
  - It has been reasonably determined that the individual does not object to the representative arrangement.
  - It has been reasonably determined that no other close relative objects to the representative arrangement, or to the procedure or treatment decision in question.
  - There are no legal barriers to involving the proposed relative representative such as a restraining order.

If the above conditions are met, the closest available relative may give treatment consents for an individual living in an ICF/MR facility that cannot give his or her own consents. There is no established hierarchy for whom this relative must be (e.g., mother, brother, aunt).

4. **Consent authority of regional centers** (W&I 4655). California law states that the director of a regional center, or his designee, may give consent to medical, dental, and surgical treatment of a regional center individual who is incapable of giving his or her own consent. This authority can be exercised when the individual has no legally authorized representative, or his or her representative does not respond within a reasonable time to a request to grant consent. An

advisory letter from the Department of Developmental Services dated January 2002 further clarified this authority to include consents “related to restrictive behavior modification techniques or treatments”.

5. **Consent authority of the medical director of a state hospital** (W&I 7518). For persons living in state developmental centers and state-operated community facilities (ICF/DD), the law authorizes the medical director of that facility to consent to medical, dental, and surgical treatments on the behalf of the individual under the following conditions:
  - The individual is mentally incapable of giving consent *and*,
  - Either the individual has no legally authorized representative, *or*
  - The individual has a legally authorized representative that does not respond in a reasonable amount of time to the request for the granting or denying of consent for treatment.
6. **Petition to the court** (Probate Code section 3200 et seq.). A petition may be filed to establish that an individual lacks capacity to make a specific health care decision, and to designate a person to make that specific decision.
7. **Guardianship and Conservatorship** (Probate Code 1400 et seq.). This is a formally adjudicated process, which results in the court appointment of a person (guardian or conservator) who oversees the personal care, and/or financial matters of another person (ward or conservatee). The power to make health care decisions can be specified in the letters appointing the guardian or conservator. If the power is specified, the guardian or conservator has the power to make health care decisions on behalf of the ward or conservatee in good faith and based on medical advice. The Director of the Department of Developmental Services can be appointed as a guardian or conservator under certain circumstances for people who have a developmental disability (H&S Code 416 and 416.5).

While a guardianship or conservatorship may be necessary to safeguard the rights of some individuals due to the complexity of their circumstances, **it is the position of the Department (DHS-L&C) that not all cases require this protection**. By its design, this process has the potential to strip a person of the very rights it seeks to protect by delegating those rights to another person. It is also expensive, cumbersome, and time-consuming, and may not be preferable given the other provisions for consent and decision-making that exist in California.

## LIMITATIONS TO SURROGACY

There are situations where the consent of the individual's conservator or the authority granted under a surrogate decision-making arrangement is not adequate to ensure protection of an individual's rights. State law (Probate Code 4652) **prohibits** consent by an agent or a surrogate for any of the following without a specific court order:

- Commitment to or placement in a mental health treatment facility.
- Electroconvulsive treatment.
- Psychosurgery.
- Sterilization.
- Abortion.

Other situations where **court intervention** may be necessary concerning treatment consents for unconserved adults in ICF/MR facilities are:

- When the individual is clearly resistive to the treatment in question.
- When there is controversy between family members regarding a health care decision.
- When the motives of the surrogate decision-maker are questionable.
- When the treatment is experimental, punitive, or aversive.

Additionally, operators and employees of the residential facility, in which an individual resides and is receiving care, are **prohibited** from acting as a surrogate or health care agent for the individual (Probate Code 4659).

## **POSITIVE PRACTICES**

Federal ICF/MR regulations require surveyors to evaluate how effectively the providers allow, and encourage the individuals in their care to exercise their rights and maximize their potential for self-determination. The issue of obtaining “Informed Consent” for treatment decisions is an important element of this larger arena of rights and self-determination, and should be viewed in this context. The process for making a determination of an individual’s need for support, assistance, training and/or representation in the exercising of their rights should begin with the regional center’s intake assessment, and continue through the comprehensive functional assessment and IPP process. The IDT is the vehicle to ensure that this assessment is done, and the specially constituted committee (also known as the human rights committee or HRC) is responsible to ensure that each individual’s needs for advocacy and/or representation are effectively addressed.

The following tables are provided as reference tools for ICF/MR surveyors and providers to use when reviewing a facility’s system for promoting and protecting individuals’ rights. **Table 1** addresses some positive practices that are related to the regulatory responsibilities of the ICF/MR provider. **Table 2** discusses the interagency roles and responsibilities of the regional center, the Department of Developmental Services (DDS), and the individual’s primary physician in obtaining informed consent.

**Table 1 - ICF/MR PROVIDER POSITIVE PRACTICES - INFORMED CONSENT**

Facility Practice	Regulatory Reference	Look for this:
<p>The facility protects individuals’ rights and includes opportunities for choice and self-management wherever possible.</p>	<p>42 CFR 483.420 (a)-(d)(4) 483.440(c)(6)(vi) 483.450(a)(1)(i)(ii) 483.450(a)(2)  (W122-157, 247, 267, 268, 269, 272)</p>	<ul style="list-style-type: none"> <li>• People are treated with respect and dignity throughout their day.</li> <li>• People are offered choices that are individualized and available throughout their lives.</li> <li>• People are given appropriate support to expand their opportunities for choice and, whenever possible, to become less dependent on others for decision-making.</li> </ul>
<p>The facility employs a system of advocacy, and proactively identifies those individuals who need assistance and support in exercising their rights.</p>	<p>483.420(a)(1)-(3) 483.420(c)(1) 483.440(c)(3)(v)(7) &amp;(9)  (W122, 123, 124, 125, 143, 213, 214, 215, 222, 224)  Also see:  <u>Title 22</u> 76313 (a) 76313(d)(2) 76859( c)(2)</p>	<ul style="list-style-type: none"> <li>• Individuals are assessed to determine the degree to which they need assistance to exercise their rights, and if representation for decision-making and consent is required.</li> <li>• Assessment begins with the pre-admission and is ongoing.</li> <li>• The primary physician is involved in assessing whether or not people have the capacity to make specific treatment decisions for themselves.</li> <li>• When individuals lack capacity to consent or are minors, authorized representatives are available to give consent for treatment.</li> <li>• People needing help to express their grievances have access to client rights advocates.</li> <li>• Individual preferences are honored as much as possible.</li> </ul>
<p>When individuals are identified as being in need of more education, supports, and/or adaptive equipment to enhance their ability to exercise their rights, these supports are provided.</p>	<p>483.420(a)(3) 483.440(a)(1) 483.440(c)(1)(2) 483.440(c)(6)(i) &amp; (vi)(d)(1) 483.470(g)(2)  (W125, 196, 206-209, 240, 247, 249, 436)</p>	<ul style="list-style-type: none"> <li>• Information about rights, treatment decisions, and choices are adapted to individuals’ intellectual levels and communication styles.</li> <li>• Assistive communication devices and adaptive materials are developed, available, and used consistently with the individuals for whom they were designed.</li> <li>• Efforts include enlisting the regional center to document the needs and actively pursue the necessary education, supports, and/or adaptive equipment.</li> <li>• Individuals are given the time and opportunity to participate in their own decision-making.</li> </ul>

**Table 1 – ICF/MR PROVIDER POSITIVE PRACTICES – INFORMED CONSENT (cont.)**

Facility Practice	Regulatory Reference	Look for this:
<p>When individuals are identified as lacking the capacity to give informed consent for health care or other treatment decisions, the facility demonstrates proactive efforts to ensure that these individuals are represented appropriately.</p>	<p>483.420(a)(3) 483.420(c)(1) 483.440(f)(3)(i) – (iii) 483.450(b)(2)</p> <p>(W125, 143, 261, 262, 263, 264, 285)</p>	<ul style="list-style-type: none"> <li>• These efforts are made in advance of the need for consent so that there are no unnecessary delays in treatment.</li> <li>• The need for representation is documented on the IPP.</li> <li>• Efforts include the IDT /HRC promoting the representation arrangement for an individual which offers the greatest autonomy while protecting their rights.</li> <li>• Efforts include enlisting the regional center to pursue representation for the individual when other appropriate agents are unavailable.</li> <li>• Providers’ efforts to ensure that individuals have appropriate representation includes documented solicitation of family members, and letters to regional center, the Regional Office of the State Council on Developmental Disabilities (area board), Department of Developmental Services and the Clients’ Rights Advocate to request assistance on the individual’s behalf with meeting this identified need. The need for representation is regularly reviewed. Solicitations are renewed at least annually if the need continues to be unmet.</li> </ul>
<p>Once advocates and/or authorized representatives are in place for an individual, the facility must continue to monitor the appropriateness of these services.</p>	<p>483.440(f)(1)(i)-(iii) 483.440(f)(2)</p> <p>(W257, 259, 260, 262, 263, 264)</p>	<ul style="list-style-type: none"> <li>• While respecting confidentiality in any attorney/individual relationship, the individual’s need for representation is periodically reassessed to ensure that he or she is afforded the greatest amount of autonomy and advocacy.</li> <li>• The HRC reviews treatment decisions posing risks to the individual’s rights, to ensure that such decisions made on behalf of the person reflect his or her wishes and/or best interests.</li> <li>• The facility has a mechanism for identifying high risk and/or controversial treatment decisions, and has developed a process for referring these treatment decisions for a second level of review (such as regional center clinical team or a hospital bioethics committee if appropriate).</li> </ul>
<p>Systems for maintaining communication and promoting involvement of authorized representatives and advocates must be in place.</p>	<p>483.420(a)(1) 483.420(c)(1)-(3)&amp;(6) 483.40(c)(2)</p> <p>(W123, 143, 144, 145, 148, 208, 209)</p>	<ul style="list-style-type: none"> <li>• Efforts are made to include designated representatives in the individual’s life to the appropriate degree.</li> <li>• Meetings reasonably accommodate the representative’s schedule and his or her attendance is encouraged.</li> <li>• Regular communication occurs between the individual (with the facility’s help when needed), the facility, and the authorized representative.</li> </ul>

**Table 2 – INTERAGENCY RESPONSIBILITY-INFORMED CONSENT**

- Task -

- Responsible Party -

Task	Regional Center	Provider	Physician	DDS
<p><u>Assessing</u> the individual’s ability to give informed consent.</p>	<p>Needs of individual are identified and reflected in the individual program plan (IPP). (W&amp;I 4646)</p> <p>The planning process for the IPP shall include conducting assessments to determine life goals, strengths, needs, barriers, concerns or problems of the individual. [W&amp;I 4646.5 (a) (1)].</p>	<p>Patient presumed to have capacity. (Probate Code 4657)</p> <p>Comprehensive Functional Assessment. (CFR W 212-224)</p> <p>ID advocacy needs, including the need for guardianship or conservatorship. [CCRT22 76313(d)(2) 76859(c)(2)]</p> <p>Allow, encourage, and protect civil and legal rights. (CFR W125) [CCRT22 76859(c)(3), 76313(d)(3)]</p>	<p>A physician determines capacity for making health care decisions. (Probate Code 4657)</p> <p>A primary physician, who makes or is informed of a determination that a patient lacks or has recovered capacity, ... shall promptly record that determination in the patient’s health care record, and communicates this to the patient and the person authorized to make decisions for the patient. (Probate Code 4732)</p>	
<p><u>Identifying</u> the need for informed consent for current and/or anticipated medical, dental, and surgical treatments.</p>	<p>Needs of individual are identified and reflected in the individual program plan. (W&amp;I 4646)</p> <p>A service coordinator is assigned the responsibility of implementing, overseeing, and monitoring each individual’s IPP. Service coordination includes those activities necessary to implement an IPP. [W&amp;I 4647(a) &amp; (b)]</p>	<p>Inform the individual and/or representative of the medical condition, the risks of treatment, and right to refuse. (CFR W124)</p> <p>Allow, encourage, and protect civil and legal rights. (CFR W125) [CCRT22 76859(c)(3), 76313(d)(3)]</p> <p>Nurse participation in interdisciplinary team. (CFR, W332) [CCRT22 76875(c)],</p> <p>Specially constituted committee reviews, approves, and monitors programs that involve risks to individuals’ rights. (CFR W261 &amp; 262) [CCR T22 76917(a)]</p>	<p>If the treatment involves the performance of a “complex” procedure, a physician must explain the nature of the treatment, the risks, the possible complications and expected benefits as well as the alternatives. [Cobbs v. Grant, 8 Cal.3d 229 (1972)]</p>	

**Table 2 – INTERAGENCY RESPONSIBILITY-INFORMED CONSENT (cont.)**

	- Task -	- Responsible Party -		
	Regional Center	Provider	Physician	DDS
	<p>Needs of individual identified and reflected in the individual program plan.</p> <p>(W&amp;I 4646)</p> <p>A service coordinator is assigned the responsibility of implementing, overseeing, and monitoring each individual's IPP.</p> <p>[W&amp;I 4647(a) &amp; (b)]</p>	<p>Inform the individual and/or representative of the individual's rights, the rules of the facility, the developmental and behavioral status, the risks of treatment, and the right to refuse.</p> <p>(CFR W123 &amp; 124)</p> <p>The specially constituted committee reviews, approves, and monitors programs that involve risks to individuals' rights.</p> <p>(CFR W261, 262, 263, 264)</p> <p>[CCR T22 76917 (a)(c) (3)(A-E), 76523(c)(3)A-(D)(4)]</p>		<p>Behavior management programs approved by DDS shall comply with legal and regulatory requirements.</p> <p>[CCR T22 76869(a)-(c)]</p>
	<p>In order to achieve stated objectives of a consumer's IPP, the regional center shall conduct advocacy for and protection of the civil, legal, and service rights of individuals with developmental disabilities.</p> <p>[(W&amp;I 4648(b)(1)]</p> <p>May give consent to medical, dental, and surgical treatment of regional center individuals</p> <p>(W&amp;I 4655)</p>	<p>Allow, encourage, and protect civil and legal rights.</p> <p>(CFR W125)</p> <p>[CCRT22 76859(c)(3), 76313(d) (3)]</p>	<p>A supervising health care provider who knows of the existence of or revocation of an advanced directive, or a designation or disqualification of a surrogate, shall promptly record its existence in the patient's health care record.</p> <p>(Probate Code 4731)</p>	<p>Where there are gaps in the system of services and supports, or no provider will provide services or supports contained in the IPP, the Department* may provide the services and supports directly.</p> <p>[W&amp;I 4648(g)]</p> <p>The "Department" refers to DDS and this responsibility is delegated by DDS to the regional center.</p> <p>For persons living in state developmental centers, and state-run community based facilities, the medical director of that facility may consent to medical, dental, and surgical treatment if the patient is mentally incapable of consenting and does not have a legally authorized representative or the representative does not respond to the request for consent within a reasonable amount of time</p> <p>(W&amp;I 7518)</p>

**Table 2 – INTERAGENCY RESPONSIBILITY-INFORMED CONSENT (cont.)**

	- Task -	- Responsible Party -		
	Regional Center	Provider	Physician	DDS
<p><u>Overseeing</u> the appropriateness of the individual consent or authorized representative arrangement for consent.</p>	<p>Assign a service coordinator with responsibility for implementing, overseeing, and monitoring each individual’s IPP.</p> <p>[W&amp;I 4647 (a)]</p> <p>The planning process for the IPP shall include...a schedule of regular periodic review and reevaluation to ascertain that planned services have been provided, that objectives have been met, and that consumers and their families are satisfied with the implementation of the IPP.</p> <p>[W&amp;I 4646.5 (a) (6)]</p> <p>Identify providers of service or supports who may not be in compliance with local, state, or federal statutes and regulations and notify the appropriate licensing or regulatory authority.</p> <p>[W&amp;I 4648 (d) (2)]</p>	<p>Allow, encourage, and protect civil and legal rights.</p> <p>(CFR W125) [CCRT22 76859(c)(3), 76313(d)(3)]</p> <p>The facility must ensure the rights of all individuals.</p> <p>(CFR W122)</p> <p>The specially constituted committee must ensure that programs that pose risks to individuals’ rights are conducted only with informed consent of individuals and legal representatives.</p> <p>(CFR W262)</p> <p>“Denial of rights” meets the criteria and documentation and reporting specified in CCR Title 17, Article 4, 50530, 50532, &amp; 50534.</p>	<p>A health care provider may decline to comply with an individual health care instruction or health care decision for reasons of conscience.</p> <p>(Probate Code 4734)</p>	<p>Establish a system to protect and advocate for the legal and civil rights of persons with developmental disabilities.</p> <p>[W&amp;I 4520 (b)].</p> <p>Contract for advocacy services to ensure the rights of individuals and provide assistance in pursuing legal remedies. Also to investigate and take action as appropriate and necessary to resolve complaints regarding unreasonable denial or punitive withholding of rights.</p> <p>[W&amp;I 4433 b)(d)(1)&amp;(2)].</p>

**ATTACHMENT H**  
**ACTIVE TREATMENT**  
**CMS STATEMENT**

**From:** Smith, Dianne E. (CMS/CMSO) [mailto:Dianne.Smith@cms.hhs.gov]  
**Sent:** Tuesday, October 09, 2007 7:14 AM  
**To:** Judy Citko  
**Cc:** Rogers, Adrienne (CMS/CMSO); ROCHE, KIM A. (CMS/CMSO)  
**Subject:** Hospice and ICF

Ms. Citko,

I am responding to your letter of 9/18/07 concerning hospice and ICF services.

Hospice Services, provided they meet the criteria found at 42CFR418.1 – 418.405 Subparts A – H and the Social Security Act 1861 (dd), are allowable and appropriate for people living in an ICF/MR and are considered to be their active treatment program. The ICF/MR regulations have never precluded Hospice Services for individuals since active treatment is predicated on identifying the individual's needs and meeting those needs.

CMS Central Office does not develop or offer training materials specific to provider training needs. All our training is for state surveyors and Medicaid agencies as well as CMS Regional Offices. As part of the CMS ICF/MR Basic and Focused Trainings, we often talk about different types of programs/services, but not in the detail provider facilities would need to be able to develop and implement said programs/services.

If you have any other questions or issues, please feel free to contact me.

Dianne Smith  
CMS – ICF/MR

**NOTE:**

42CFR, Part 418 covers federal regulations for hospice care. 42CFR418.1 – 418.405 Subparts A – H cover General Provisions and Definitions (Subpart A); Eligibility, Election and Duration of Benefits (Subpart B); Conditions of Participation: General Provisions and Administration (Subpart C); Conditions of Participation: Core Services (Subpart D); Conditions of Participation: Other Services (Subpart E); Covered Services (Subpart F); Payment for Hospice Care (Subpart G); and Coinsurance (Subpart H).

These regulations implement section 1861(dd) of the Social Security Act, which specifies services covered as hospice care and the conditions that a hospice program must meet to participate in the Medicare program.

# ATTACHMENT I

## DO NOT RESUSCITATE (DNR)

Informational Sheet for

Intermediate Care Facilities/Developmentally Disabled - Habilitative or Nursing

Compiled by Elaine Rawes RN (2007)



The American Heart Association points out in its 1992 *Guidelines for Cardiopulmonary Resuscitation and Emergency Cardiac Care*, emergency cardiac care should attempt to restore those hearts too good to die, and not attempt to restore hearts too sick to live.

### The definition of a Do-Not-Resuscitate (DNR) Order is:

“A physician’s written order instructing health care providers not to attempt cardiopulmonary resuscitation (CPR) in the case of cardiac or respiratory arrest. A person with a valid DNR order will not be given CPR under these circumstances.” (Partnership for Caring Inc.)

The California Medical Services Authority defines DNR as:

- a. **Do Not Resuscitate (DNR)** means no chest compressions, defibrillation, endotracheal intubation, assisted ventilation, or cardiotoxic drugs.
- b. The patient should receive full palliative treatment for pain, dyspnea, major hemorrhage, or other medical conditions.
- c. Relief of choking caused by a foreign body is usually appropriate, although if breathing has stopped and the patient is unconscious, ventilation should not be assisted.

A DNR order is not a **DO NOT TREAT** order and does not address the application of life sustaining treatment or palliative care.

DNR is a health care decision which individuals who live in ICF/DD-H and N facilities, or their authorized representative, have a right to make. There is no regulatory prohibition against this. There are restrictions that a provider must consider regarding the level of nursing care that can be safely provided in an “H” or “N” facility, and if a client is in deteriorating health these issues must be explored. Questions about a client’s specific level of care should be discussed with the Regional Center representative and/or the local Licensing & Certification field office.

The issue of a DNR order has huge implications relating to informed consent. For adults who lack the capacity to understand the risks/alternatives and are not conserved, this area is extremely complicated and probably should be discussed with an attorney or clients rights advocate. State and federal laws regarding the obtaining of informed consent from the legally appropriate representative for the client apply to the DNR treatment decision.

As with all treatment decisions, the higher the risk of the decision, the more careful and thoroughly it should be scrutinized. The decision to withhold any treatment to a client in an ICF/DD-H or N must be made with utmost care and consideration. The discussion of the DNR should begin with the client’s physician and be based on a medical assessment of diagnosis, current condition, prognosis, and as best as can be determined, the client’s wishes, values and preferences as related to their health status. The physician should provide appropriate documentation regarding the clinical indications for a DNR order.

The decision to pursue a DNR order should involve input and direction from the interdisciplinary team, including the client as appropriate, the family or authorized representative, and Regional Center Case Coordinator.

The Human Rights Committee and the Regional Center clinical team or bioethics committee, may be utilized as a level of review to assure that this decision is appropriate and in the client’s best interests.

**IF**, the client and family or authorized representative, the physician, and Interdisciplinary Team agree that DNR is appropriate for an individual in an ICF/DD-H or N, then the physician must give an **order** and obtain written informed consent for this treatment decision.

It is the ICF provider's **responsibility** to develop plans, policies and procedures which address the following:

- Training for medical emergencies, change of condition, and the role of both licensed and unlicensed staff in these situations.
- Health care plans for the DNR client with clear, specific parameters and instructions for routine care and anticipated events.
- How and where end of life care for this client is to be managed (hospital vs. home).
- Use of outside resources such as Hospice or the local Emergency Medical Services (EMS).
- Periodic review of the DNR decision.

## **RESOURCE INFORMATION:**

- DNR Guidelines: <http://www.emsa.ca.gov/aboutemsa/dnr.asp>
- DNR FAQ: <http://www.emsa.ca.gov/aboutemsa/dnrquestions.asp>
- Local EMS Agency List: [http://www.emsa.ca.gov/Ems\\_lems/lemsa.asp](http://www.emsa.ca.gov/Ems_lems/lemsa.asp)
- End of Life Care: <http://www.caringinfo.org/resources>



California  
Department of  
Health Services

**SANDRA SHEWRY**  
Director

State of California—Health and Human Services Agency  
**Department of Health Services**



**ARNOLD SCHWARZENEGGER**  
Governor

**ATTACHMENT J**

June 15, 2005

AFL 05-24

TO: ALL LONG TERM CARE HEALTH FACILITIES

SUBJECT: PRE-HOSPITAL DO NOT RESUSCITATE FORMS

Enclosed please find important information from the California Emergency Medical Services Authority (EMSA) regarding the Emergency Medical Services (EMS) Pre-hospital Do Not Resuscitate forms (DNR). This information does not represent new standards or procedures. It is being provided to long term care facilities to promote awareness regarding the availability of this state-wide form. The EMS Pre-hospital DNR form has been developed by EMSA in collaboration with the California Medical Association and EMS providers and is designed to instruct EMS providers to forgo resuscitation efforts in the event of a patient's cardiopulmonary arrest while in a pre-hospital setting such as in a long term care facility or while on transport to or from a facility. It does not take the place of the facility's own system for documenting the DNR wishes of an individual.

The Department of Health Services, Licensing and Certification program has received recent reports that some long term care facilities have presented improper DNR documents to EMS teams who have responded to a 911 call for their resident. A DNR form that is not legally acceptable or readily recognizable by the paramedic or Emergency Medical Technician results in confusion, and when in doubt as to the legality of the document, emergency response professionals have been taught to err on the side of giving care to the patient. The use of the EMS Pre-hospital DNR Form is encouraged to avoid this kind of confusion, and thereby ensure that the resident's wishes are honored in pre-hospital situations.

For more information, and copies of the EMS Pre-hospital DNR Form, please go to the EMSA website at: [www.emsa.ca.gov](http://www.emsa.ca.gov). The form is available in either PDF or Word format and is free of charge.

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Page 2  
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For questions regarding this letter, please contact Jocelyn Montgomery, Disaster Preparedness Coordinator, Licensing and Certification at (916) 552- 9365 or [jmontgo2@dhs.ca.gov](mailto:jmontgo2@dhs.ca.gov).

Sincerely  
**Original Signed by Brenda G. Klutz**

Brenda Klutz  
Deputy Director

Attachment:

cc: California Emergency Medical Services Authority  
1930 Ninth Street  
Sacramento, CA 95814

California Association of Health Facilities  
2201 K Street  
Sacramento, CA 95816-4922

AFL 05-24  
Attachment A  
June 15, 2005

THE FOLLOWING INFORMATION IS PROVIDED FROM THE CALIFORNIA  
EMERGENCY MEDICAL SERVICES AUTHORITY WEBSITE.  
FOR ADDITIONAL INFORMATION GO TO, [www.emsa.ca.gov](http://www.emsa.ca.gov)

CALIFORNIA EMERGENCY MEDICAL SERVICES AUTHORITY  
(EMSA) Web Site - Revised 4/8/2005

SUBJECT: DO NOT RESUSCITATE (DNR) ADVANCE DIRECTIVES FOR EMSA  
FREQUENTLY ASKED QUESTIONS AND ANSWERS

What is a DNR Form?

A DNR Form (actual title: "Emergency Medical Services Prehospital (DNR) Form) is an official State document developed by the California EMS Authority and the California Medical Association which, when completed correctly, allows a patient with a life threatening illness or injury to forgo specific resuscitative measures that may keep them alive. These measures include: chest compressions Cardio Pulmonary Resuscitation (CPR), assisted ventilation (breathing), endotracheal intubations, defibrillation, and cardiotoxic drugs (drugs which stimulate the heart). The form does not affect the provision of other emergency medical care, including treatment for pain (also known as "comfort measures"), difficulty breathing, major bleeding, or other medical conditions. Many patients make their DNR wishes officially known because they do not want to be placed on life-assisting equipment in the event that their heart or breathing ceases.

1. Are there State guidelines covering the use of the DNR Form?

Yes, you may download the EMS Authority's "Guidelines for EMS Personnel Regarding DNR Directives" via our website at [www.emsa.ca.gov](http://www.emsa.ca.gov) (access [Publications # 111](#)). You may also wish to contact the local EMS agency for your county to obtain a copy of their local DNR policies, which will be based on the State Guidelines, but may have additional specifications.

2. How can I ensure that the Emergency Medical Technician or paramedic responding to my emergency needs will honor my DNR wish?

The best way to ensure that your wishes are honored is to complete the official State Prehospital DNR form and have it signed by your physician and readily accessible when EMS help arrives. If you are concerned about the form being

available at all times, you would be well-advised to obtain and wear a Medic Alert bracelet or neck medallion engraved with your DNR requirements.

3. How can I obtain a DNR form?

You may go to the EMSA website and download a form in either [Microsoft Word format](#) or in [Adobe PDF format](#). These wording on these forms are not to be modified in any way except to include the required information of patients name, date signed by patient, surrogate's relationship to patient, physician date signed, physician printed name and physician phone number. The EMSA keeps a small supply of paper forms for individual request to have a form mailed to you, or call us at (916) 322-4336. If you wish to have a larger supply, you should contact the California Medical Association publications office directly, at (415) 882-5175.

4. How and I obtain a Medic Alert bracelet?

Bracelets may be ordered through the [Medic Alert Website](#). The Medic Alert organization has 24-hour toll-free line: 1-888-755-1448. Please not that Medic Alert is a registered trademark, and substitute identifier bracelet may no be recognized by the EMT or paramedic.

5. What if the EMT can't find the DNR form or evidence of a Medic Alert medallion? Will they withhold resuscitative measures if my family ask the too?

No EMS personnel are taught to proceed with CPR when needed. Unless they are absolutely certain that a qualified DNR advance directive exists for the patient. If, after spending a reasonable (short) amount of time looking for the form or medallion, they do not see it, they will proceed with lifesaving measures.

6. What if I change my mind? Can I reverse my DNR orders?

Absolutely. Your DNR orders are in place for as long as you wish them to be; you need only to destroy them if you wish to stop them. You should also contact your doctor's Office and family if you do so.

7. Can the State DNR form and/or Medic Alert medallion be used in a skilled nursing facility or hospice?

Yes. We encourage the adoption of the form for use by such facilities; however, many facilities do no know of the form. Or they have their own in place, which

may not be recognizable by the EMT or paramedic. If you have concerns about the ability of the responding EMS personnel to be able to follow your DNR wishes, you would be well advised to obtain and wear a Medic Alert bracelet or medallion.

8. What about other legal documents, such as a Durable Power of Attorney for Health Care (DPAHC?) or “living wills”. Are they acceptable in place of the Prehospital DNR form?

While such official documents are generally respected by EMS personnel (check with your attorney and with the local EMS agency in your county), it is important to keep in mind that most EMTs or paramedics do not have the legal training needed to interpret such documents, and more importantly, do not have time to read a lengthy document and make a life-or-death decision on the scene. They have been taught to err on the side of the patient, if they are in doubt (in other words, to provide life support). If you want to follow the advice given in the answer to question number three, above.

9. Where can I get other information about end-of-life care in California?

One such organization is the [California Coalition for Compassionate Care](#). The Coalition is a statewide partnership of over 50 regional and statewide organizations dedicated to the advancement of palliative medicine and end-of-life care in California.

10. Is this form and the Medic Alert Medallion used in other states?

Each state has its own DNR policies and procedures and accompanying paperwork. Some states are more specific than California, some less. Only about eight states currently use the Medic Alert brand of ID bracelets. And some use wallet cards instead. If you are traveling out of state, you may wish to contact the state’s EMS office or public health department to determine what you will need to do to ensure that your DNR wishes will be followed. There is a list of [state EMS agencies](#) to contact on the EMSA Website.

Medicare  
Learning  
Network

**PAYMENT  
SYSTEM  
FACT SHEET  
SERIES**

**CMS**  
CENTERS FOR MEDICARE & MEDICAID SERVICES



**Hospice  
Payment System**



**Hospice Care** is an elected benefit covered under Part A for a beneficiary who meets all of the following conditions:

- The individual is eligible for Part A;
- The individual is certified as having a terminal disease with a prognosis of six months or less if the illness runs its normal course;
- The individual receives care from a Medicare-approved hospice program; and
- The individual signs a statement indicating that he or she elects the hospice benefit and waives all rights to Medicare payments for services for the terminal illness and related conditions. Medicare will continue to pay for covered benefits that are not related to the terminal illness.

Medicare may provide the following hospice services for the terminal illness and related conditions:

- Doctor services;
- Nursing care;
- Medical equipment;
- Medical supplies;
- Drugs for symptom control or pain relief;
- Home health aide and homemaker services;
- Physical therapy;
- Occupational therapy;
- Speech-language pathology services;
- Social worker services;



- Dietary counseling;
- Spiritual counseling;
- Grief and loss counseling for the individual and his or her family;
- Short-term care in the hospital, including respite care; and
- Any covered medically necessary and reasonable services as identified by the interdisciplinary team.

Medicare will NOT pay for the following services when hospice care is chosen:

- Treatment intended to cure the terminal illness;
- Care from any provider that was not set up by the elected hospice;
- Care from another provider that is the same care that the individual must receive from his or her hospice;
- Services not covered by Medicare; and
- Services that are not medically reasonable and necessary.

## **CERTIFICATION REQUIREMENTS**

For the first 90-day period of hospice coverage, the hospice must obtain a certification of the terminal illness by the medical director of the hospice or the physician member of the hospice interdisciplinary team and the individual's attending physician (if he or she has an attending physician) no later than two calendar days after hospice care is initiated. Only a medical doctor or a doctor of osteopathy can certify or recertify a terminal illness. An attending physician is a doctor of medicine or osteopathy or a nurse practitioner who is identified by the patient, at the time he or she elects to receive hospice care, as having the most significant role in the determination and delivery of his or her medical care.

Written certification must be on file in the patient's medical record prior to submission of a claim to

the Fiscal Intermediary or A/B Medicare Administrative Contractor and must include:

- A statement that the patient's medical prognosis is that his or her life expectancy is six months or less if the terminal illness runs its normal course;
- Specific clinical findings and other documentation that supports a life expectancy of six months or less; and
- Signature(s) of the physician(s).



If the individual lives longer than six months, he or she is still eligible for hospice care as long as there is recertification of the terminal illness.

## ELECTION PERIODS

Hospice care is available for 2 periods of 90 days and an unlimited number of 60 day periods. The individual must waive all rights to Medicare payments for the duration of the election of hospice care.

The election statement includes the following information:

- Identification of the particular hospice that will furnish care to the individual;
- The individual or representative's (if applicable) acknowledgement that he or she has been given a full understanding of hospice care;
- The individual or representative's (if applicable) acknowledgement that he or she understands that certain Medicare services are waived by the election;
- Effective date of the election; and
- Signature of the individual or representative.

An individual or representative may revoke the election

of hospice care at any time. In order to revoke the election, the individual must file a document with the hospice that includes a signed statement that he or she revokes the election of hospice care for the remainder of that election period and the effective date of that revocation. The individual forfeits any remaining days in that election period and his or her Medicare coverage of the benefits waived is resumed.

An individual may change the designation of the hospice from which he or she elects to receive hospice care once in each election period. In order to change the designated hospice, the individual must file a signed statement with both the hospice from which he or she has received care and with the newly designated hospice. The statement includes the following information:

- The name of the hospice from which he or she has received care;
- The name of the hospice from which he or she plans to receive care; and
- Date the change is to be effective.

## HOW PAYMENT RATES ARE SET

Medicare pays hospice agencies a daily rate for each day a beneficiary is enrolled in the hospice



benefit. The daily payments are made regardless of the amount of services furnished on a given day and are intended to cover costs that the hospice incurs in furnishing services identified in patients' care plans. Payments are made based on the level of care required by the beneficiary:

- Routine home care;
- Continuous home care;
- Inpatient respite care; and
- General inpatient care.

The daily hospice payment rates are adjusted to account for differences in wage rates among markets. Each category of care's base rate has a labor share and a nonlabor share. The labor share of the base payment amount is adjusted by the hospice wage index. Base rates are updated annually based on the hospital market basket index.

The fiscal year 2008 payment rates for the period October 1, 2007 through September 30, 2008 increased by 3.3 percentage points of the 2007 payment rates, as depicted in the chart below.

There are two caps that apply to the hospice benefit:

- 1) The number of days of inpatient care it may furnish is limited to not more than 20 percent of total patient care days; and
- 2) An aggregate payment amount that is based on the number of Medicare patients electing the benefit within the cap period.

The hospice aggregate cap is adjusted annually by the medical expenditure category of the Consumer Price Index for all Urban Consumers. For the cap year ending October 31, 2007, the cap is \$21,410.04.

For claims with dates of service on or after January 1, 2008, hospices must report on claims the Core Based Statistical Area for the location where services are furnished for all levels of hospice care.

To find additional information about the hospice benefit, see the Hospice Center Web Page located at <http://www.cms.hhs.gov/center/hospice.asp>.

This web page also contains a link to hospice program transmittals and hospice manual information (Chapter 9 of the **Medicare Benefit Policy Manual**, Pub. 100-02, and Chapter 11 of the **Medicare Claims Processing Manual**, Pub. 100-04).

### Fiscal Year 2008 Hospice Payment Rates

Code	Description	Rate	Wage Component Subject to Index	Non-Weighted Amount
651	Routine Home Care	\$135.11	\$92.83	\$42.28
652	Continuous Home Care Full Rate = 24 hours of care \$32.86 hourly rate	\$788.55	\$541.81	\$246.74
655	Inpatient Respite Care	\$139.76	\$75.65	\$64.11
656	General Inpatient Care	\$601.02	\$384.71	\$216.31

This fact sheet was prepared as a service to the public and is not intended to grant rights or impose obligations. This fact sheet may contain references or links to statutes, regulations, or other policy materials. The information provided is only intended to be a general summary. It is not intended to take the place of either the written law or regulations. We encourage readers to review the specific statutes, regulations, and other interpretive materials for a full and accurate statement of their contents.

The Medicare Learning Network (MLN) is the brand name for official CMS educational products and information for Medicare fee-for-service providers. For additional information visit the Medicare Learning Network's web page at <http://www.cms.hhs.gov/MLNGenInfo> on the CMS website.

#### Medicare Contracting Reform (MCR) Update

In Section 911 of the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 (MMA) Congress mandated that the Secretary of the Department of Health and Human Services replace the current contracting authority under Title XVIII of the Social Security Act with the new Medicare Administrative Contractor (MAC) authority. This mandate is referred to as Medicare Contracting Reform. Medicare Contracting Reform is intended to improve Medicare's administrative services to beneficiaries and health care providers. All Medicare work performed by Fiscal Intermediaries and Carriers will be replaced by the new A/B MACs by 2011. Providers may access the most current MCR information to determine the impact of these changes and to view the list of current MACs for each jurisdiction at <http://www.cms.hhs.gov/MedicareContractingReform> on the CMS website.