

The background features several large, overlapping, curved arrows in shades of purple, green, and blue. Interspersed among these are several small, yellow, triangular shapes that resemble sun rays or sparks. The overall aesthetic is clean and modern, with a focus on movement and positivity.

# **Key Strategies for Implementation of Pediatric Palliative Care in the Military Health System**

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# ***m*CARE**

Military Children at Risk: Enhancing  
the quality of life



# *m*CARE

- Funded by Congressional appropriation in DOD budget from Cong. Murtha
- Process: research proposal subject to external peer review
- Approach: designed as feasibility study to assess implementation of pediatric palliative care in the MHS



# **mCARE: Project Goals**

- Identify unique needs of families, providers
- Understand authorized care, services
- Assess availability, accessibility and barriers to resources, services
- Ascertain gaps in provision of care
- Provide recommendations, implementation strategies to TMA



# **mCARE: Components of project**

- Family, provider needs assessments
  - Qualitative research design with IRB approval
- Assessment of resources, services
  - Analysis availability, accessibility & barriers
- Analysis of Tricare benefit
- Identification target population, eligibility criteria
- Site visits to existing PPC programs

# MILITARY HEALTH SYSTEM

- Benefit established by Congress
- Administered by TRICARE Management Activity (TMA), DOD/HA
- 2 avenues of care
  - Direct care: MTFs
  - Purchased care: Managed care support contractors
    - 3 regions CONUS
    - TRICARE OCONUS
- Benefit: Basic, ECHO
- Multiple programs
  - Prime, standard, remote
  - TRICARE for Life (Medicare-eligible)
  - Benefits vary for active duty, retirees





# Analysis of Benefit


- Case management variable, often not care coordination
- Home health care only for children with high level disability, dependents of active duty members
- Home health care requires skilled nursing need
- Hospice benefit guided by Medicare/Medicaid criteria, only in Medicare approved facilities
- Bereavement counseling excluded unless MH diagnosis





# Analysis of Benefit

What is missing:

- Care coordination with written plan of care
  - Home health care, respite care with flexibility on skill level of provider
  - Bereavement counseling not linked to traditional mental health services
  - Ability to provide supportive care to enhance QOL concurrent with life-sustaining treatment
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# Gap Analysis

- Processes are needed to improve families' access to needed services.
- Comprehensive care coordination and continuity of care is vital.
- The complexity and duration of care needed by children with life-threatening conditions creates challenges that require extra coordination.
- A medical home is generally not available to children with special needs.
- Administrative challenges sometimes create barriers to access.



# Gap Analysis

- Families and providers are not trained or equipped to advocate for these children.
- Many providers are inadequately trained in effective communication techniques for palliative care.
- Concepts of family-centered care, informed decision making are practiced with varying levels of knowledge, resources, support, and effectiveness.
- Children and families have many unmet needs for both emotional support and social support.
- Limited knowledge and resources are available to families for financial advice or support



# Gap Analysis

- Not all clinical and pastoral counselors are qualified to provide counseling for the initial diagnosis of a life-threatening condition or issues related to a dying child.
- There are few formalized pediatric palliative care programs.
- End-of-life care for children is inconsistent.
- Both providers and families lack sufficient knowledge about pediatric palliative care.
- Military issues create unique problems and added stress.

# Critical Components of Pediatric Palliative Care



Education and information for providers and families

Care coordination





# MHS: Unique Challenges

- Population is worldwide
  - Military treatment facilities (MTF) vary in size, staff, resources
  - Primary focus of care is on adults, particularly active duty personnel
  - Benefit determined by Congress
    - No flexibility with purchased care providers or options
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# MHS: Unique Opportunities

- Active duty families may be relocated based on their medical needs.
- Military hospital commanders have flexibility to utilize their budget, resources within their MTF however they chose.

A decorative graphic on the left side of the slide features three balloons: a light green one at the top, a light blue one in the middle, and a light purple one at the bottom. Each balloon is attached to a streamer with several small yellow triangular flags. The balloons have a slight shadow and a highlight, giving them a 3D appearance.

# Essential Program Elements

- Program champion
- Site assessment
- Interdisciplinary team with care coordination
- Education of providers and families
- Appropriate end of life support



# Essential Program Elements

Program champion:

- Respect and credibility
- Passion and knowledge
- Practice evidence-based medicine
- Willingness to educate colleagues on pediatric palliative care



# Essential Program Elements

## Site assessment:

- Determine size, demographics of population
- Assess available personnel, services
- Evaluate existing community resources

## Interdisciplinary team:

- Creative, flexible, designed around family needs
- Single care coordinator

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# Essential Process Elements

- Interdisciplinary, family-centered approach
- Individualized written plan of care
  - Reflects choices of child, family
  - Has flexibility as needs change
- Measures of quality of care, outcome, family satisfaction



# **mCARE: Model Options**

- Dedicated team, direct care
- Consultative team with primary care provider
- In-patient, out-patient or both
- Focus on particular populations
  - Highest risk
  - Underserved
- Focus on particular process
  - Education
  - Care coordination



# *m*CARE: Essential Elements of Model

- Identification of a program champion
  - Education of all stakeholders
  - Process for interdisciplinary approach
  - Written comprehensive plan of care
    - Flexible
    - On-going reassessment of needs
  - **Care coordination**
  - Quality assurance/outcome measures
    - Clinical outcomes
    - Quality of care, patient satisfaction outcomes
    - Financial outcomes
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