



## General Considerations

*BQIS Fact Sheets provide a general overview on topics important to supporting an individual's health and safety and to improving their quality of life. This document provides general information on the topic and is not intended to replace team assessment, decision-making, or medical advice. This is the first of four Fact Sheets regarding palliative care.*

## Intended Outcomes

To provide information related to the definition, purpose, care, interventions, and strategies that are considered palliative care.

## Definitions

**Palliative care:** The active, all-encompassing care of people that prevents and provides relief from pain, suffering, and discomfort and maximizes their quality of life.

## Facts

- The goal of palliative care is to keep the individual free from pain, suffering, and discomfort or to keep pain, suffering, and discomfort sufficiently controlled so it does not interfere with their ability to function or their quality of life.
- Each individual communicates pain or discomfort in their own way.
- It is important that caregivers know the signs and symptoms of the individual's pain.
- Individuals with intellectual and developmental disabilities (IDD) often express pain with:
  - Increased or decreased motor activity, e.g., involuntary movement, resistance to movement, lying down, touching hurting body part
  - Facial activity, e.g., eyes closed tight, tense face, grimacing or furrowed brow
  - Social-emotional indicators, e.g., wanting to be left alone, refusing to do usual activities, signs of fear, distress, or anxiety, signs of frustration or irritability, low mood or depression
  - Non-verbal expression, e.g., crying, screaming, moaning, groaning
  - Physiological indicators, e.g., increased or difficult respiration, tears, facial redness
  - Verbal expression that is location-specific, e.g., "My head hurts", or non-location specific "I don't feel good"
  - Aggression, e.g., throwing things, destroying property, tantrums, acting out, challenging behavior
  - Eating/sleeping changes, e.g., eating more or less than usual, sleeping more or less than usual



- Additional symptoms depending on the individual
- Signs and symptoms that can contribute to discomfort include:
  - Nausea and vomiting
  - Fever
  - Intractable hiccups

### Recommended Actions and Prevention Strategies

1. Coordinate a variety of health and support services to maximize potential for management of pain, suffering, and discomfort.
2. Use a comprehensive pain assessment and pain rating scale to measure and ensure pain/discomfort relief and management.
3. Keep the individual's pain under control through frequent assessment, evaluation, and implementation of pain relief strategies.
4. Train all staff on all aspects of palliative care including pain monitoring and management, completion of pain assessments, and pain rating scales.
5. Determine if additional adaptive equipment or positioning devices are needed to help with pain management. An occupational therapist can help in determining which types may help.
6. Assist and support the individual to maintain functional capacity and independence.
7. Train staff to provide non-medication pain relief measures such as: relaxation measures, back rubs, soft music and aromatherapy, as approved by the physician.
8. Refer the individual to a palliative care program through local hospital if available and/or to occupational therapy and/or physical therapy as needed, and as per physician's orders/recommendations for comfort measures to reduce pain and discomfort such as relaxation therapy, heat, diathermy, massage, ROM (range of motion) exercises, etc.
9. Make sure there is a pain management protocol or plan in place including but not limited to:
  - Listing of signs/symptoms of pain and discomfort for the individual
  - Unique ways the individual expresses pain and discomfort



- Frequent assessment of pain and discomfort
- Strategies for addressing pain and discomfort and thresholds for implementation of strategies
- Ways to document pain, interventions, and reactions

### Learning Assessment

The following questions can be used to verify a person's competency regarding the material contained in this Fact Sheet:

1. True or false: Palliative care focuses on all aspects of the individual's care.
2. True or false: Each individual has their own ways to communicate pain.
3. Some good ways to measure pain include:
  - A. Pain assessments
  - B. Pain rating scales
  - C. Observation for nonverbal signs of pain
  - D. All of the above
4. True or false: Training is not necessary for staff to complete palliative care measures.
5. Pain relief and comfort measures that do not involve medication could include all except:
  - A. A back rub
  - B. Stimulating fast paced music
  - C. Relaxation measures
  - D. Aromatherapy



## References

Adams, D. and Oliver, C. (2011). *The expression and assessment of emotions and internal states in individuals with severe or profound intellectual disabilities*, *Clinical Psychology Review*, 31, 293-306. Retrieved 08/20/2015 from: [http://eprints.bham.ac.uk/1426/1/Adams\\_%26\\_Oliver\\_\(2011\).\\_The\\_expression\\_and\\_assessment\\_of\\_CPR.pdf](http://eprints.bham.ac.uk/1426/1/Adams_%26_Oliver_(2011)._The_expression_and_assessment_of_CPR.pdf)

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## Related Resources

*Palliative Care Series Fact Sheets: "Pain Management", "Comfort Measures", "Adaptive Equipment"*

*Pain Assessment Rating Scale*

*Pain Management Diary*

## Learning Assessment Answers

1. True
2. True
3. D
4. False
5. B