

# “Will You Remember Me?”

## Talking with Adolescents About Death and Dying

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### KEYWORDS

- Adolescents • Advance care planning • Decision-making • End-of-life
- Palliative care

### KEY POINTS

- Talking with adolescents who have a life-threatening or life-limiting illness is one of the most difficult tasks a health care provider (HCP) can undertake.
- A necessary and important first step in learning how to speak with adolescents about death or dying is assessing one's own readiness as an HCP.
- Adolescents want to be included in medical decision-making through the illness trajectory including making decisions around end-of-life.
- Prognosis is not necessary before initiating advance care planning discussions.

### INTRODUCTION

Talking with adolescents who have a life-threatening or life-limiting illness is one of the most difficult tasks a health care provider (HCP) can undertake. In the past, medical providers, parents, and the public have thought that conversations about dying, advance care planning (ACP), and end-of-life discussions should be avoided with medically ill youth.<sup>1</sup> This was due to a desire to protect children and adolescents or due to beliefs that they do not understand death and dying or do not have the capacity to make decisions about their own health. However, modern Western society has come to understand that these difficult conversations are not only often beneficial for patients and families but also are increasingly considered the standard of care. Today, the American Academy of Pediatrics,<sup>2</sup> the Institute of Medicine,<sup>3</sup> and the World Health Organization<sup>4</sup> recommend involving youth in decisions regarding their health

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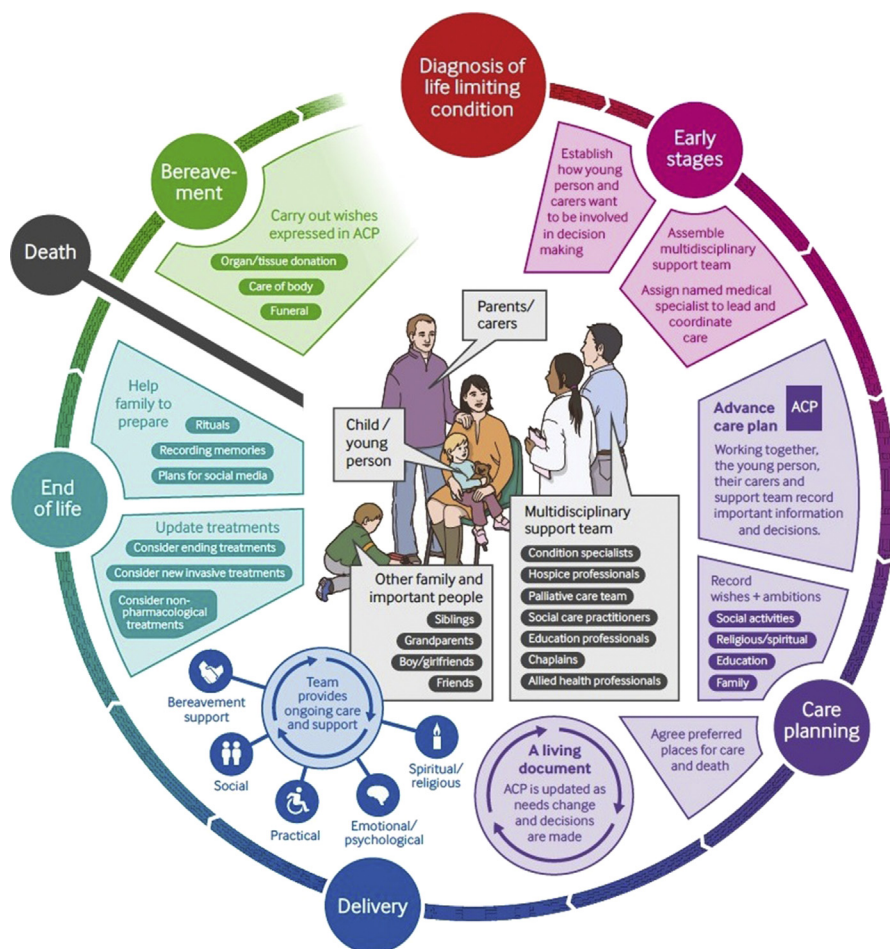
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care decisions as they are developmentally and emotionally ready. This article focuses on the following:

1. Adolescents who have a life-limiting condition and their understanding of death,
2. Developmental considerations around health care decisions, and
3. A practical approach to engaging adolescents in conversations around ACP, including addressing barriers to communication, especially at the end-of-life (Fig. 1).<sup>5</sup>

## HISTORICAL PERSPECTIVE

As recently as the 1970s, revealing a cancer diagnosis to a child was considered inhumane. Researchers believed that children and adolescents were not aware of their impending deaths and that the stigma of a cancer diagnosis should not be shared



**Fig. 1.** End-of-life care for children and young people. (From Villanueva G, Murphy MS, Vickers D, et al. End of life care for infants, children and young people with life limiting conditions: summary of NICE guidance. *BMJ* 2016;355:i6385; with permission.)

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