

## ***Leaving A Legacy: Adolescent and Young Adult End-of-Life Care Planning***

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### INTRODUCTION

End of Life (EoL) care has expanded into a vital component of medical practice, as patients and their providers partake in pertinent discussions before it is too late. These efforts have historically focused largely on the geriatric population, leaving out the younger patients whose needs must also be considered. Each year, more than 11,000 adolescents and young adults (AYAs) aged 15-34 die from cancer and other life-threatening conditions.[1] Traditionally, grief-stricken parents are forced to make decisions on their adolescent or young adult child's behalf, often with little guidance as to what their child would have wanted. Although parents of patients under 18 serve as the legal decision-maker, this does not mean that the patients do not want to have a say in how they spend their last days, or what happens after their death. It is now strongly suggested that providers approach the young adults directly, allowing them to voice their opinions and document their preferences. An innovative planning guide has paved the way in assisting AYAs with life threatening illnesses convey their choices, opening up avenues for crucial and compassionate conversations previously not discussed. A shift is beginning to take place as whispered conversations outside a patient's room between doctor and parent are replaced with candid and collaborative discussions focused specifically on the patient's desires.

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## ANALYSIS

The planning-guide that has received such praise, Voicing My CHOICES™, is the first of its kind to be produced for—with the input from—adolescent and young adult patients. It was designed with the intention to offer patients with a life threatening illness the opportunity to have a voice in a wide range of important matters, from naming a health care agent and making decisions on the extent and types of life support they want, to how they would like to be comforted, supported, and remembered. Voicing My CHOICES™ also allows AYAs to voice preferences on funeral/memorial planning, as well as organ/body donation, if they desire to do so. The guide was developed by researchers at the Pediatric Oncology Branch of the National Cancer Institute and the National Institute of Mental Health at the National Institutes of Health (NIH). This team of researchers worked with AYAs over the course of approximately 10 years to evaluate interest in a developmentally appropriate advance care planning guide, review Five Wishes® (an existing advance care planning guide for adults), and assess helpfulness and stressfulness of EoL care planning. AYAs also reported preferences on guide content, format and design.[2] Using the qualitative and quantitative data, NIH researchers created a guide specifically for AYA patients. Voicing My CHOICES™ differs from adult guides in that it incorporates color, simplified wording, and a glossary of terms. Most importantly, it addresses issues most developmentally appropriate for AYAs, including additional questions pertaining to peer relationships and the legacy they wish to leave behind.[3] Since its publication by the non-profit, Aging With Dignity, in October 2012, more than 20,000 copies have been distributed both nationally and internationally to over 70 medical centers. The widely successful guide has since been translated into Spanish, Italian, French and Slovak.[4]

The movement to include young patients in their own EoL planning faces many challenges. Doctors are not always properly trained to approach these topics with AYAs, as such a delicate topic requires careful conversation. There also permeates a widespread thought that AYAs may not be able to fully comprehend EoL care needs, or worse, would be psychologically harmed by such a discussion. Some providers also worry that parents or patients might not respond positively to the guide in fear that by participating, they are signaling a loss of hope for the future. For an older individual, who has lived longer and perhaps taken the time for thoughtful reflection, this conversation might come with less anxiety and less surprise than for a young patient— one who needs to plan for EoL while he or she is just beginning to form a sense of identity, develop independence and plan for the future.

However, the overwhelmingly positive response from patients and parents, thus far, demonstrates that this novel guide should be incorporated into all AYA EoL care. The key to effectively spread this initiative involves training healthcare providers to appropriately present the information. Intuition and empathy, although crucial components, are not enough to guide doctors and other providers in discussing EoL options for patients. Health care providers must also hone effective communication skills to guide their patients through the difficult, yet ultimately gratifying, process of voicing their choices. Fortunately, the developers of the guide released guidelines on how to best introduce such conversations and how to effectively utilize an advance care-planning guide.[5] It is recommended that EoL discussions be a routine part of clinical care, begin near to the time of diagnosis, and continue throughout the course of a patient's care.

## CONCLUSION

Not only can the guide help give a voice to the patients, but it can also lift a weight off of the overwhelmed parents who can begin to feel at ease knowing that they can honor their child's preferences. With the aid of provocative questions like "what gives you strength or joy" and "what do you wish to be

forgiven for,” patients who have felt powerless can begin to claim at least some control over a situation that has felt out of their control. This guide can help assuage the common fear among medically ill AYAs that they are too young to leave a lasting legacy. It is actually this exact time in life when one begins to explore his or her identity and cultivate a sense of self. With the guidance of compassionate health care providers, these patients can now move forward with the comfort of knowing their voices have been and will continue to be heard.