

Spreading HoPE: Helping patients and families access information about hospice through a web-based app

BASS CONNECTIONS

Roadmap for Evaluating Goals in Advanced Illness Navigation (REGAIN)

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Introduction

Patients and families who have been referred to hospice face many concerns. They may experience stress related to a new diagnosis or decline in health condition, lack proper knowledge of hospice services, or may have had prior bad experiences with hospice. At this sensitive time, people want to be able to make informed decisions about their care. While information about hospice is widely accessible, no hospice-focused decision aids are publicly available to help patients and families navigate this challenging time.¹ Hence, we developed Hospice Preparation and Education (HoPE) to help patients and families learn about hospice, think about what is important to them, and prepare for a hospice admission visit. The aim of HoPE is to improve hospice conversion rates (from referral to admission).

Development Process

Learning Phase

We interviewed hospice providers and admissions personnel from Duke Homecare and Hospice and Transitions LifeCare to understand common questions and concerns of patients and families referred to hospice. We reviewed current hospice education materials from national and state associations and hospice education groups.

Production Phase

We developed an app workflow, wrote scripts for videos and activities, explored UI/UX designs, coded the app, and established the database infrastructure.

Review Phase

The palliative care research group at Duke, clinical staff at Duke and Transitions LifeCare, and the Patient and Family Advisory Council at Duke Homecare and Hospice provided critical feedback on app prototypes.

Fig. 1: HoPE Workflow

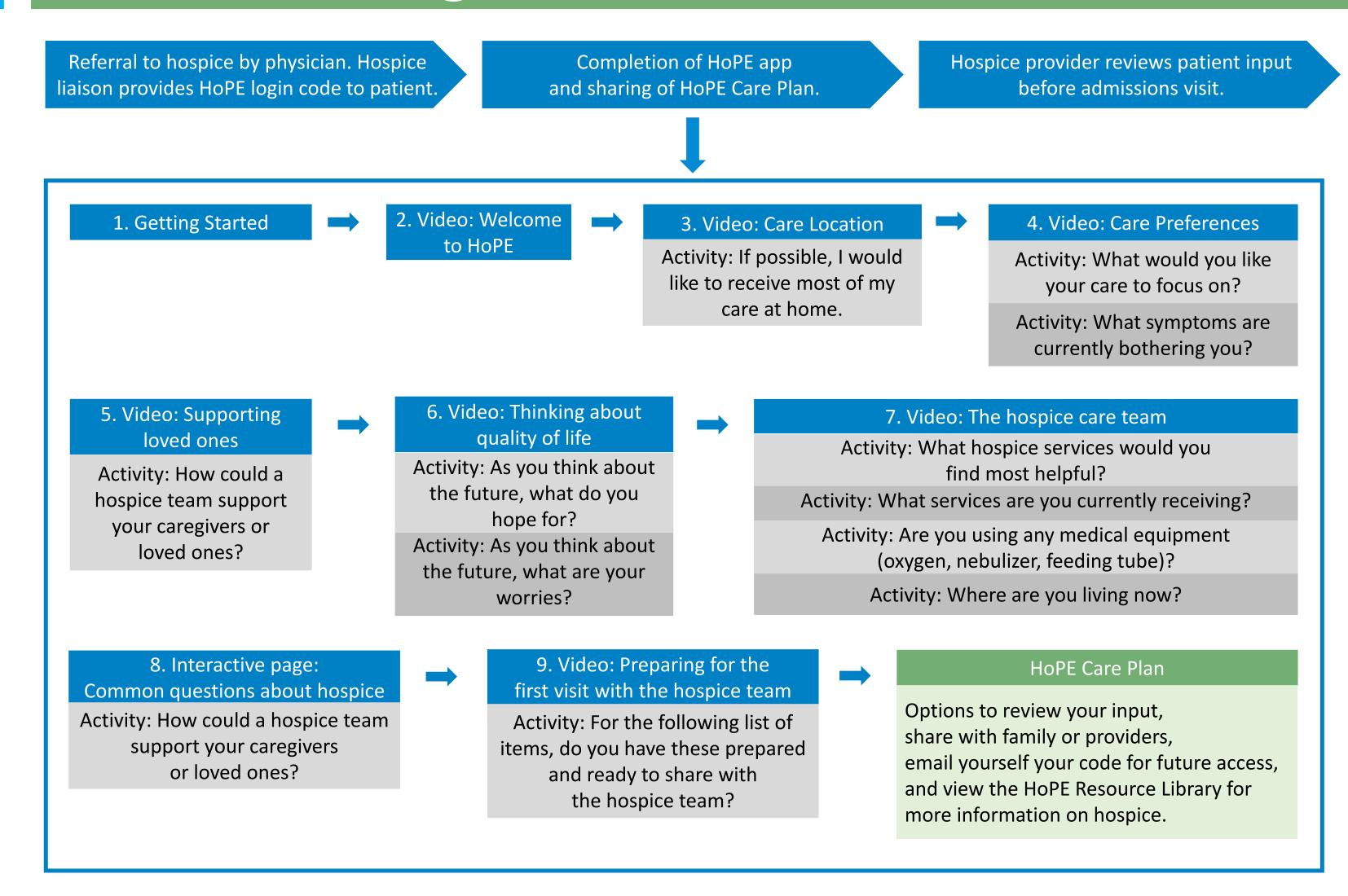


Fig. 2: HoPE Landing Page

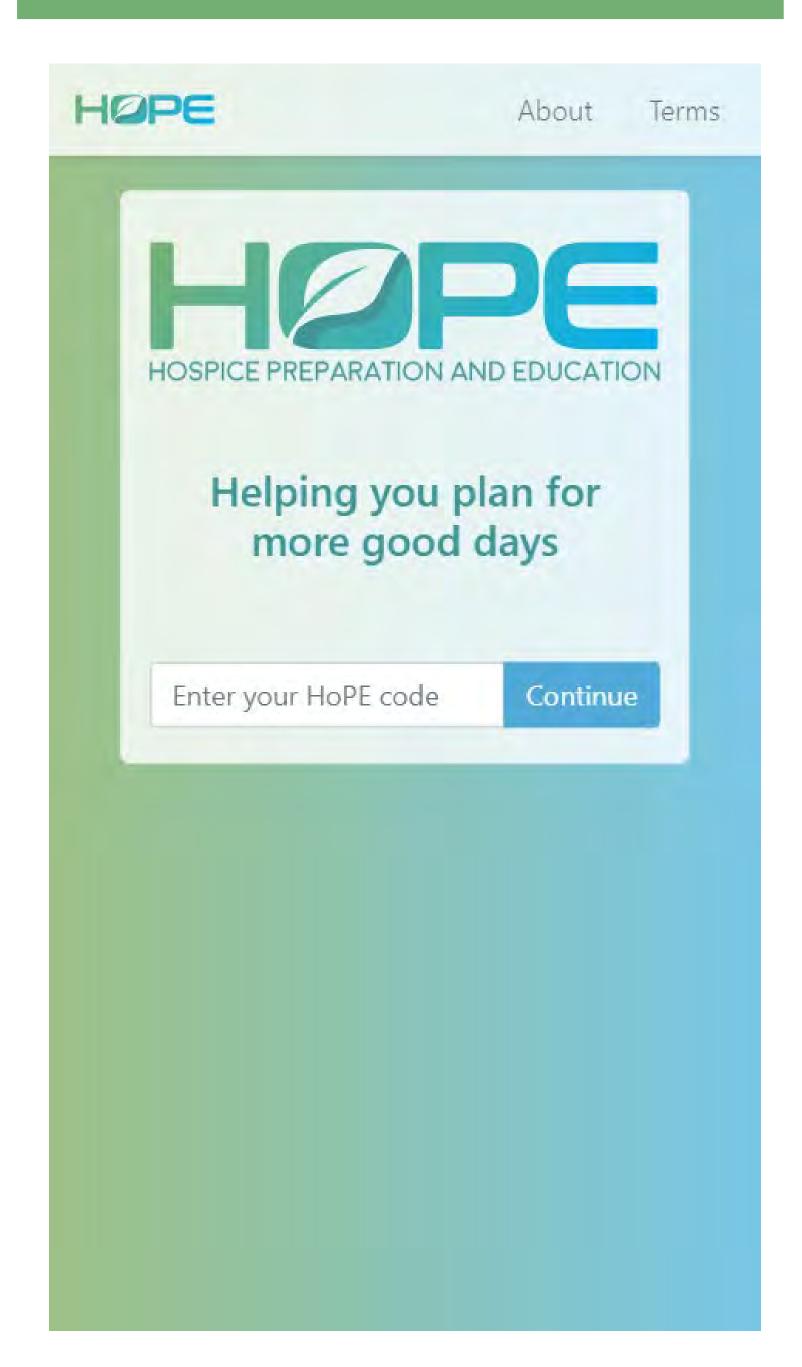
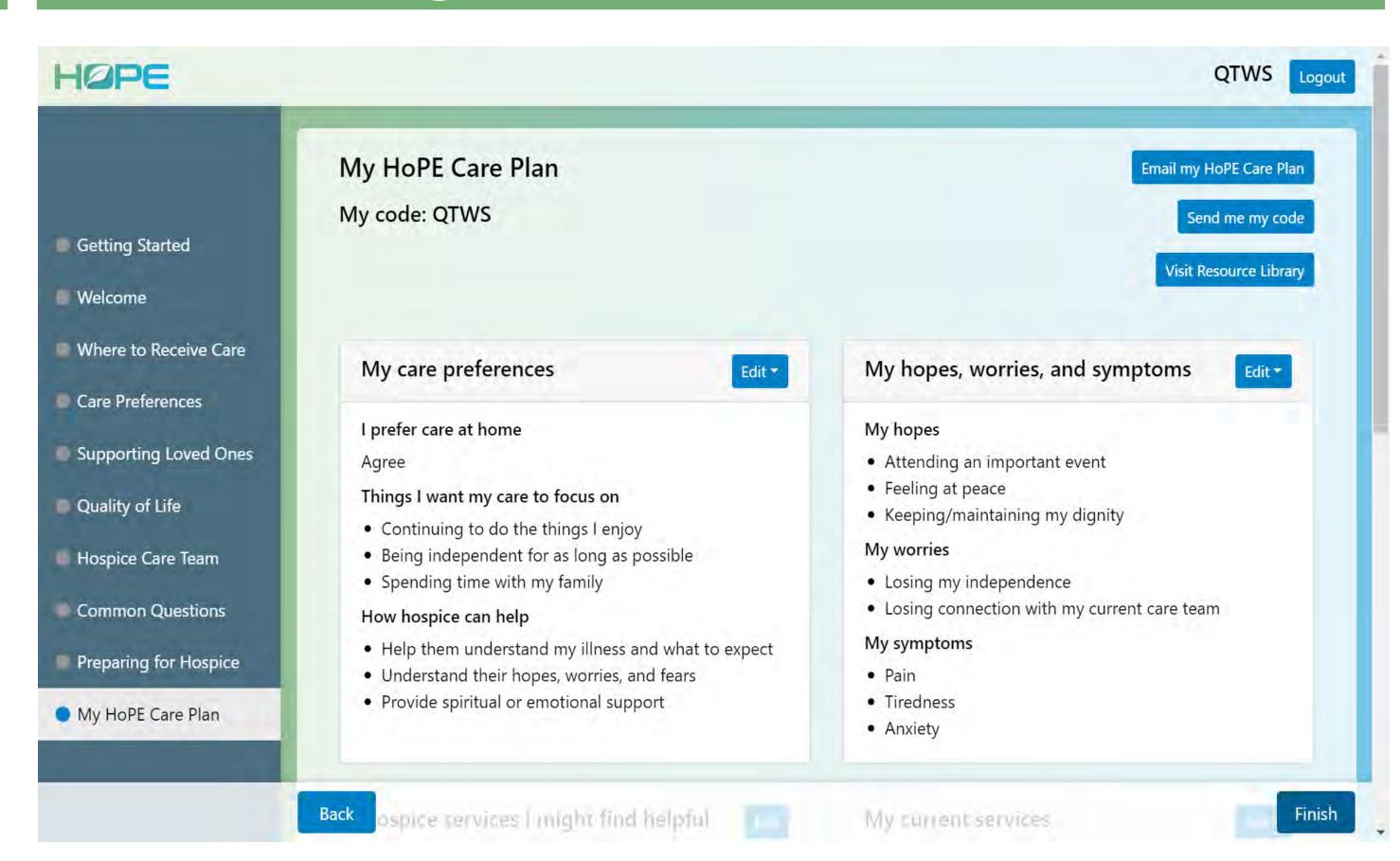


Fig. 3: Hopes and Wishes Activity



Fig. 4: HoPE Care Plan



Key Features of HoPE:

- > HoPE is usable on desktop, tablet, and smartphone.
- > At each step, animated videos introduce a topic. Patients complete activities to delineate care preferences.
- > A HoPE Care Plan documenting these care preferences is generated. Patients can share this with hospice providers and family, promoting communication of goals of care.
- > Institution-specific administrative portals allow hospice providers to autonomously generate login codes for patients and view patient progress and Care Plans.

Next Steps

- > Pilot trial with Duke Homecare and Hospice and Transitions LifeCare.
- > Dissemination to hospices and hospital systems.

Reference

1. Finnegan-Fox, G. Matlock, D.D., Tate, C.E., Knoepke, C.E., Allen, L.A. (2017). Hospice, she yelped: examining the quantity and quality of decision support available to patient and families considering hospice. Journal of Pain and Symptom Management 54(6) 916-921. doi: 10.1016/j.jpainsymman2017.08.002.