



# Survivorship Resource Guidebook

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## Introduction

**Background:** Pediatric brain tumors afflict children of all ages. In the U.S., more than 28,000 children and teenagers live with the diagnosis of a primary brain tumor (1). In 2017, an estimated 4,820 new cases of childhood primary malignant and non-malignant brain and other central nervous system tumors were expected to be diagnosed in children ages 0 – 19 in the United States. The five-year relative survival rate for this group is nearly 75 percent (2). Nevertheless, survivors suffer from lifelong side effects caused by their illness or by various treatments such as surgery, radiation and chemotherapy. Commonly identified late effects of treatment include a decline in intellectual functioning and processing speed, performance IQ deficits, memory deficits, psychological difficulties, deficits in adaptive functioning (daily life skills), and an overall decrease in health-related quality of life. As one study powerfully concludes, individuals with brain tumors face consequential and wide-ranging effects across their lifespan: “Compared to controls, childhood brain tumor survivors are less likely to marry, complete high school, maintain employment, or receive appropriate health care. Brain tumor survivors face additional problems related to motor, sensory, and behavioral disturbances, often culminating in social isolation and failure to attain independence” (3).

**Project Summary:** In response to the results of its recently published community health needs assessment elucidating the challenges survivors of childhood brain tumors face, the Pediatric Brain Tumor Foundation developed and published in 2019 a comprehensive **Survivorship Resource Guidebook**. The guidebook addresses the challenges these survivors face and categorizes their needs into three primary areas: physical and mental health, quality of life, and working the system. This poster will describe key outcomes discovered during the creation and production of this resource and highlight how caregivers, survivors and professionals collaborated to provide needed information and practical help to one segment of the pediatric cancer population who experience profound morbidities as a result of their diagnosis and treatment.

Targets include adolescent and young adult pediatric brain tumor survivors (and their caregivers), a group the literature demonstrates are at profound risk for physical, cognitive and psychosocial late effects from diagnosis and treatment.

**Goals and Objectives:**  
Goal: To create a relevant, comprehensive **Survivorship Resource Guidebook** for pediatric brain tumor survivors and their families.

- Objectives:**
- 1) Engage pediatric brain tumor families and healthcare professionals in development of guide material from creation of outline through writing of content to final review.
  - 2) Conduct a health literacy review of guide content and pre-test within target population and professionals in the field.
  - 3) Promote and distribute finished product to target population and pediatric institutions of excellence across the U.S.

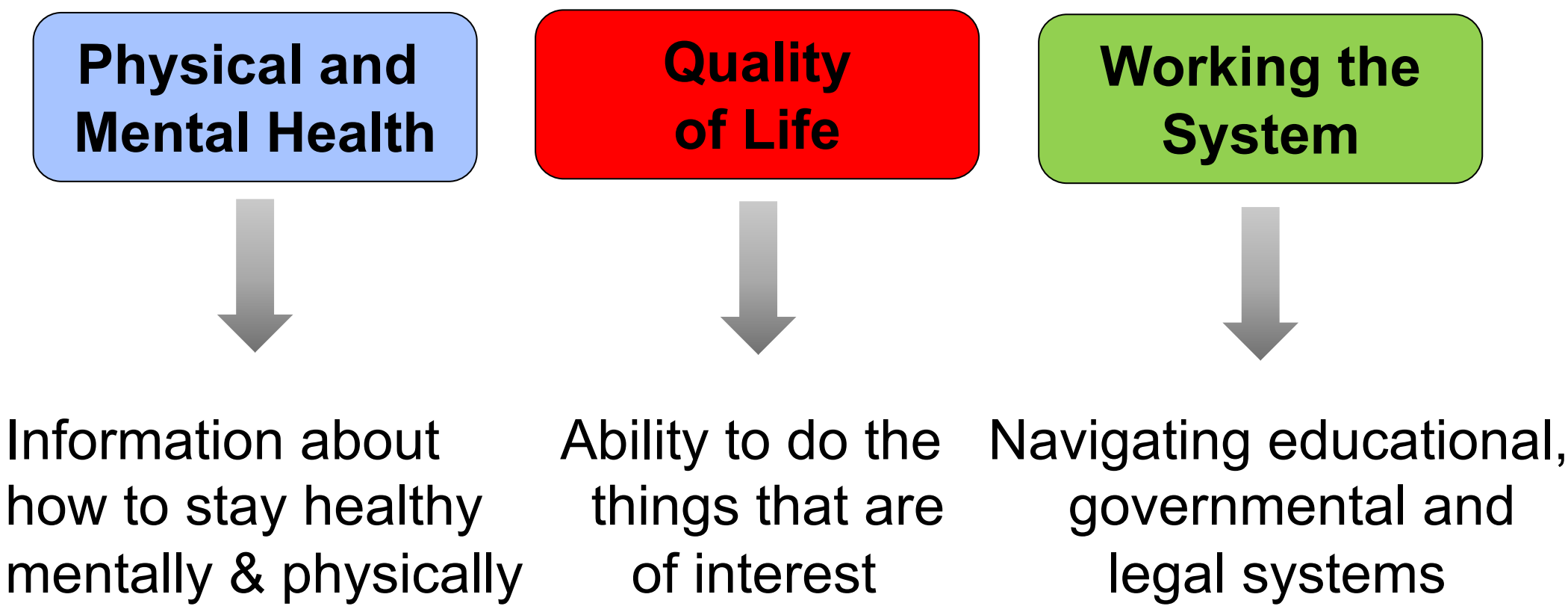
## Methods



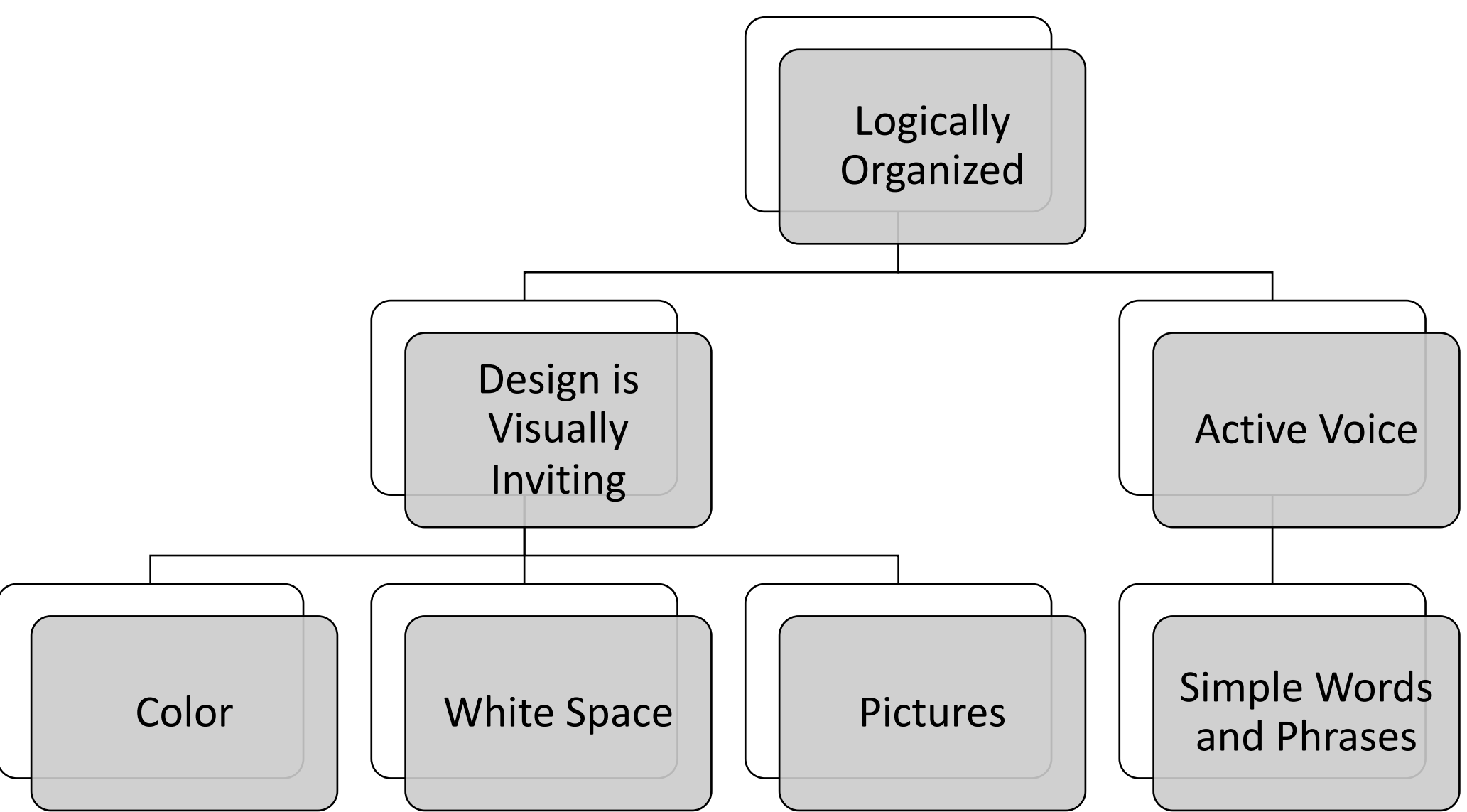
### A Work of Collaboration:

- Health educators, survivors and caregivers developed outline for **Survivorship Resource Guidebook** content
- Survivors, caregivers and healthcare professionals reviewed outline and provided feedback on content
- Survivors, caregivers, and healthcare professionals were recruited to write content:
  - 1) 21 healthcare professionals
  - 2) 11 parents of pediatric brain tumor patients
  - 3) 6 pediatric brain tumor survivors

### Content Areas Were Developed in Three Categories:



### Guided by Health Literacy Best Practices: [www.plainlanguage.gov](http://www.plainlanguage.gov)



## Methods (cont'd)

- Development of Content:**
- Total of 43 content areas developed in three categories
  - Separate survivor and caregiver perspectives included
  - A resources section titled “What Has Helped”
  - Nine medical record-keeping templates ranging from healthcare contact information to a survivorship care plan
  - Journal prompts for a survivor to record their story and the people and goals that matter most to them
  - Available as a downloadable PDF and a hard copy

### Sampling of Late Effects of Treatment section:

What late effects should you watch for?

Exercise and nutrition

Genetic counseling and family risk

Problems with thinking and learning

Psychological trauma and emotional distress

- Development of Reviewer Form:**
- Recruited two parents of survivors as reviewers
  - Recruited one survivor as a reviewer
  - Recruited four healthcare professionals as reviewers

### Healthcare professionals responded to the following questions or statements:

- 1) Review for medical accuracy – flag any areas of concern and suggest a more accurate way to state information.
- 2) Is there any information crucial to survivors of pediatric brain tumors that's missing from the notebook?
- 3) Is there any information in the notebook that should not be there?
- 4) On a scale of 0-10, 0 being not at all suitable and 10 being entirely suitable, how suitable is this resource for your population of pediatric brain tumor survivors and families? What are the primary reasons for your rating?

## Conclusions

- Project Outcomes:**
- 1) Conducted focus groups with caregivers and survivors to crystalize guidebook content areas that are most relevant to the pediatric brain tumor journey.
  - 2) Engaged caregivers, survivors, and professionals in the field to write and review the guidebook content.
  - 3) Recruited a health literacy writer to translate content into a single uniform voice written at a level accessible to the target audience which includes young adult survivors with cognitive impairments.
  - 4) Pre-tested guidebook content with target population. Revise content in response to target population feedback.
  - 5) Promoted and distributed the notebook to over 400 individuals from the target population within the first year of release.
- 38 experts contributed to the content in the final version, including top experts in the field of pediatric brain tumors and several expert pediatric brain tumor survivors and parents.
  - Downloaded in 33 states
  - Downloaded in 14 countries
  - Over 400 downloads or hard copies have been distributed in the last 9 months.

**Feedback from Survivors and Healthcare Professionals:**

“This handbook is an absolutely marvelous, thoughtful and inspiring work and I have no doubt it will help many families, caregivers, survivors and physicians care for this very special population.”

“Thank you so much for sending me the above book! It arrived in today's mail and I can't put it down. I'm learning all about 'me'! I also look forward to sharing this with my parents who, I'm sure, can relate to most of the information as well, especially the caregiver sections which I am not able to although I do have a better perspective of what they went through since I've had my own children. I only wish that I had this resource thirty years ago! Again, thank you very much for making this resource available and especially for sending me a free copy. It is greatly appreciated!”

### References

1. Porter K.R., McCarthy B.J., Freels S., Kim Y., & Davis F.G. (2010). Prevalence estimates for primary brain tumors in the US by age, gender, behavior, and histology. *Neuro-Oncology*, 12(6):520-527.
2. Central Brain Tumor Registry of the United States. (2017). 2016 CBTRUS fact sheet. Retrieved from <http://www.cbtrus.org/factsheet/factsheet.html>.
3. Castellino S.M., Ullrich N.J., Whelen M.J., & Lange B.J. (2014). Developing interventions for cancer-related cognitive dysfunction in childhood cancer survivors. *Journal of the National Cancer Institute*, 106(8):1-16. doi:10.1093/jnci/dju186.

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