

# Bringing Social Context Into the Conversation About Pediatric Long-term Ventilation

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Decisions to initiate long-term ventilation (LTV) for children with medical complexities often involve unclear risk/benefit ratios. Although the technology may prolong a child's life, the added months to years could largely be spent in the hospital, a long-term care facility, or medical foster care, as well as at home. Clinicians who counsel families about initiating LTV must help them make value-based decisions that account for each child's medical needs and the predicted experience with the technology. That experience depends substantially on how well the family can manage daily care at home: how well they can learn the necessary skills, dedicate the required time, and garner adequate support. Because the success of long-term technologies rests on home care provided by families, each family's social context is relevant to the decision to initiate pediatric LTV. Social context (the physical, geographic, economic, and cultural circumstances in which children and their families live) will impact the child's outcome; those children with medical complexity combined with adverse social factors have the poorest health among all children.<sup>1</sup>

A recent study showed that ~2% of PICU patients across the United States received a tracheostomy and LTV; almost all of these children had chronic medical conditions.<sup>2</sup> Substantial variability was noted in the postdischarge support systems provided to these medically complex patients and their families. Regional resources, such as home nursing, medical day care, and medical transportation, can reduce burdens for this population, but they receive inconsistent local, state, and federal support. Considerable caregiving demands for families managing home medical equipment are well described and can entail employment changes, geographic relocation, or disruption of family structure.<sup>3</sup> Clinicians striving to individualize decisions about LTV generally have a limited window into the social context that shapes what it will be like for this child to go home with this family. Similarly, families faced with decisions about LTV for their children may not know how to think through the implications for changes to life at home.

Evidence for how to consistently, meaningfully, and fairly incorporate family social contexts into decisions about LTV has not kept pace with the availability of pediatric home medical equipment. The essential question is can this family provide the necessary home care if LTV is initiated for the child? And, if not, what would the alternatives look like, and are they acceptable to the family? These decisions require frank consideration of the child's and the family's potential experience of the treatment alternatives: complex home care, indefinite inpatient care, medical foster care, or limiting life-sustaining therapies. Reviewing potential home care demands and alternative placements during decisions about initiating LTV may not be helpful for every family, but consistently offering tangible discussions of child and family quality of life with LTV legitimizes and explores these concerns for any

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family that wishes to engage in this discussion. We have previously argued that high-stakes medical decisions ought to regard social challenges in addition to medical need<sup>4</sup>; in this article, we will review the practice gaps that must be addressed to establish a systematic approach to integrating medical and social information so as to meaningfully augment family decisions.

Consider this case: Hannah Baker is a 3-month-old with Chiari II malformation and myelomeningocele with no movement of her lower extremities. After initial surgical repair, she developed hydrocephalus and required a ventriculoperitoneal shunt. During these 3 months in the hospital, Hannah has had profound central apnea and frequent desaturation and bradycardia episodes, requiring bag ventilation and, often, brief cardiopulmonary resuscitation. Her neurodevelopmental prognosis is uncertain. The ICU team has attempted to separate Hannah from mechanical ventilation and failed; they now believe Hannah will require LTV. The option of tracheostomy and LTV are considered.

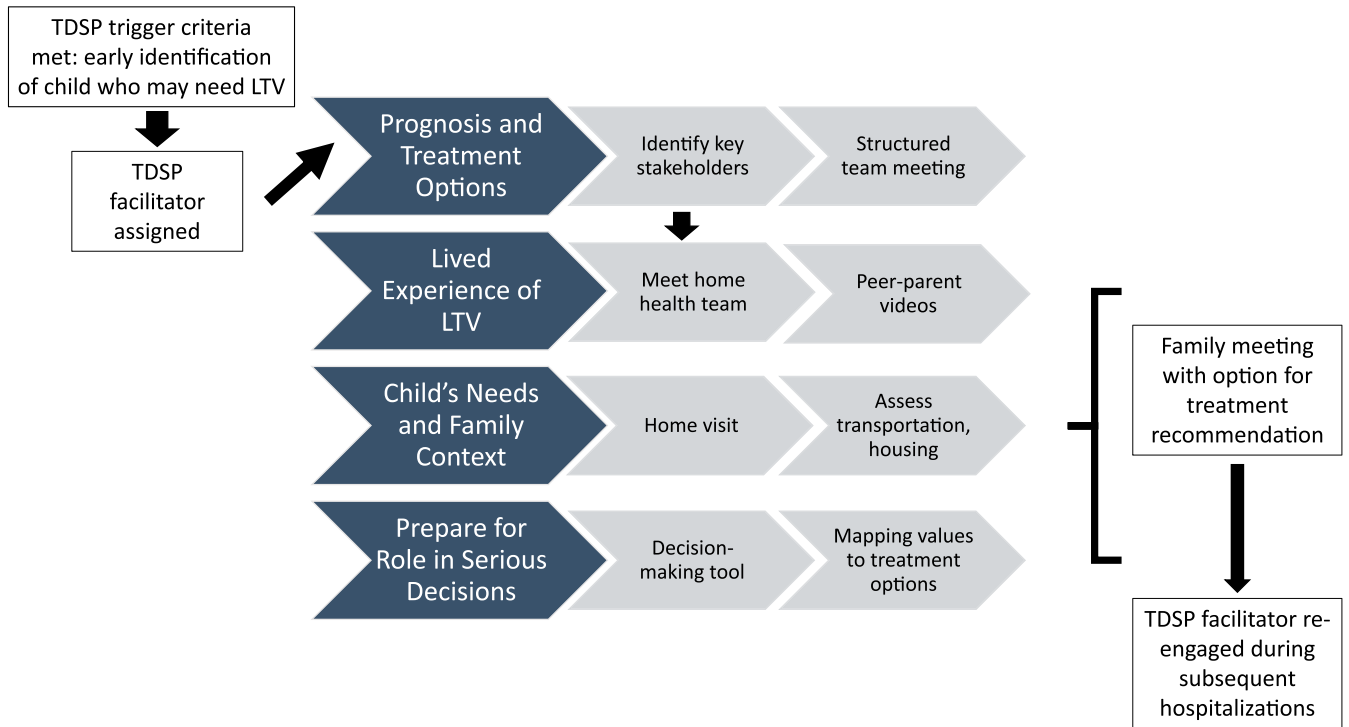
A comprehensive and deliberative approach to the decision regarding LTV for Hannah should include (1) seeking a consensus about her medical and/or neurodevelopmental prognosis and treatment options; (2) providing rich information to her family about the lived experience of those with LTV; (3) mapping her medical needs to her family's physical, economic, and cultural circumstances; and (4) preparing her family members for their role in serious medical decisions. In standard practice, a variety of practice gaps can prevent medical teams from achieving these goals. Clinician consensus about a child's prognosis, for example, may be unclear for lack of an appointed leader as well as a timely and systematic process for synthesizing the child's medical information, consultant opinions, and relevant testing, results, and literature.<sup>5</sup> In addition, preparing families for the lived experience of LTV may be limited to inpatient discussions led by clinicians and might not incorporate the true experts, other families. The evaluation of the family's home

environment and social vulnerabilities before initiating LTV for the child may not extend beyond a social work consult. Finally, families may be presumed to know how to join in serious medical decisions for their children despite the fact that parents often lack relevant experience with serious illness.

To build on the evidence that exists<sup>6</sup> and address ongoing gaps in the decision-making process, we propose a technology decision support process (TDSP) that could provide structure and consistency to deliberations regarding any pediatric advanced technology, such as LTV, that requires complex home care. The TDSP could systematically combine discrete tools and practices, augmenting current care through intentional and consistent use. Locally available resources would shape TDSP content, process, and personnel, although we believe that maintaining several core elements will prevent it from devolving into less comprehensive or systematic approaches. Initiating the TDSP early is essential to reducing the number of days that the child is sedated, paralyzed, etc while the decision regarding LTV is being considered. This would require developing specific clinical triggers, which could be activated on ICU admission (eg, facial and/or airway anomalies or congenital hypoventilation), after specific clinical events (eg, failed extubation), or during ongoing screening (eg, a weekly assessment of which ventilated ICU patients meet criteria for chronic critical illness).<sup>5</sup> A consistent facilitator is crucial to coordination and continuity; this individual would need communication skills training, a toolkit of protocols for important discussions, and dedicated funding that would reflect the number of children locally who would require the TDSP. Proactive exploration of family and community resources should address practical barriers to home care before a child undergoes invasive procedures, such as a tracheostomy, and commences LTV; this could occur for all families and could draw on existing tools for social context appraisals.<sup>7,8</sup> Helping parents hear from other families, both those who have made decisions to provide technologic supports

and those who decided not to, is important, perhaps via video testimonials. Finally, participants with expertise in navigating and clarifying complex goals of care (for example, bioethics and palliative care consultants) should be included.

Practically, a clinical trigger would initiate the TDSP (for example, a child's prolonged mechanical ventilation in the ICU; Fig 1). The clinical trigger would activate the continuity facilitator, perhaps a nurse, who will be the force for integrating information from the medical team and family. The trained facilitator becomes the central point of contact for the family, the clinical team, and all TDSP members. The facilitator could follow a structured meeting guide<sup>9</sup> to convene the key medical stakeholders; assess whether there is a clinician leader for the decision at hand; explore the relevant medical information, clinical goals, and treatment options; and establish a consensus about future steps. Once the child's medical and neurodevelopmental prognosis is clear and clinicians agree that LTV is probably feasible for the child, the facilitator engages TDSP members to provide targeted information to and gather targeted information from the family. Ideally, a home visit is part of this process, helping the family and the team to achieve a more nuanced understanding of how the child's LTV would impact the home environment and day-to-day family life. Once these activities are completed, the facilitator would join the medical team and the family to discuss the decision about LTV. For families that opt for LTV, the facilitator could remain engaged with the family longitudinally and revisit elements of the TDSP as needed during any future decisions regarding medical technologies for the child. Table 1 illustrates the different personnel who might be responsible for elements of the TDSP. A hospitalist or pulmonologist could be well situated to sponsor the TDSP at his or her institution, perhaps incorporating it into existing clinical programs for inpatient management, transitions to other care sites, and discharge from the hospital for children with LTV.



**FIGURE 1** The technology decision support process.

Consider this example of how the TDSP could unfold for Hannah Baker:

**TDSP facilitator:** The facilitator meets with the ICU attending and Hannah's primary nurse to note which clinicians should be involved with important discussions and decisions for Hannah. The facilitator organizes and conducts a meeting with these clinicians (some attend by phone) by using a structured format to review Hannah's prognosis and the proposed treatment options.

**Key information learned:** The treatment options include tracheostomy and LTV with home care or long-term inpatient care versus foregoing interventions and transitioning to compassionate extubation and comfort care. There is not unanimous clinician agreement about the best treatment option for Hannah, and no one feels that any options should be removed from consideration. The facilitator arranges to join the ICU attending, hospitalist, and ear, nose, and throat (ENT) surgeon to discuss prognosis and treatment options with Hannah's family, the Bakers.

**ICU attending:** The ICU attending tells the Bakers that Hannah's prolonged need for intubation means she may not be able to come off the ventilator. He presents the treatment options to the family with relevant pros and cons.

**Key information learned:** The family is presented medically sound options for Hannah. The ICU attending confirms that a decision must be made and that it is important for the medical team to understand what the family thinks is best for Hannah.

**ENT surgeon:** The surgeon shares a video with the Bakers that demonstrates what a tracheostomy looks like, how it works, and what happens during the surgery. She introduces a team that teaches parents how to care for a trach, how to address common problems, and what to do in an emergency. She informs the Bakers that many children with a tracheostomy can eventually learn to talk and eat.

**Key information learned:** The Bakers seem to grasp the complexity of tracheostomy care. They hear that Hannah's need for LTV would likely be permanent.

**Hospitalist and pulmonologist:** The hospitalist describes the typical hospital course for children with LTV, including issues of nutrition and functional rehabilitation. She also confirms a high risk of rehospitalization during acute infections. The pulmonologist who will care for Hannah's LTV needs describes the extensive training and discharge planning that are necessary to arrange the complex home care that Hannah would need. He or she also begins preparing the Bakers for the care coordination that would be their responsibility given the many different health care providers involved in the different portions of inpatient and outpatient care for children with LTV.

**Key information learned:** The Bakers hear that children with LTV are at risk for recurrent and prolonged hospitalizations. They also hear that Hannah will need a full-time caretaker at home and close outpatient supervision.

**TDSP facilitator:** Now that the treatment options for Hannah are clear and discussions have started regarding the lived experience of LTV, the facilitator

**TABLE 1** TDSP Team: Potential Composition, Expertise, Tools, and Tasks

Potential Team Member <sup>a</sup>	Expertise	Tools and Tasks
Child's prognosis and treatment options		
Facilitator		
ICU clinician		
Surgical specialist (eg, ENT)	Long-term medical and neurodevelopmental prognosis	Identify key clinician and/or provider stakeholders in the child's care
Subspecialists	Likelihood of decannulation	Convene structured team meeting to reach a consensus about prognosis and treatment options before meeting with the family
Hospitalist	Alternatives to LTV	
Respiratory therapist	Procedural considerations	
Developmental pediatrician		
Speech therapy		
Lived experience of LTV		
Facilitator		
Pulmonologist		
Respiratory therapist	Usual hospital course for child with LTV	Home health team demonstrates equipment and care tasks parents would have to learn
Home health provider	Practical skills and daily home care	Pulmonologists describe potential sites of care
Primary care clinician	Outpatient care coordination and medical home	Parents watch videos of other parents describing their decisions
Hospitalist	Likely rehospitalizations	
	Other parents' experiences of choosing or declining LTV	
Subspecialists		
Other parents		
Mapping child's needs to family social context		
Facilitator	Family supports (eg, extended family and respite)	
Social work	Health literacy and capabilities (eg, ability to learn LTV care)	Psychosocial evaluation tool (eg, modified SIPAT <sup>6</sup> )
Case management	Conflicting obligations (eg, siblings and jobs)	Home visit
Home health provider	Community resources (eg, home nursing and medical day care)	Assess availability of and eligibility for home nursing
Palliative care support	Financial considerations (eg, insurance, transportation, and housing)	Explore transportation options
Prepare family for role in serious decisions		
Facilitator	Considering the child's interests and quality of life	
Palliative care support	Impact on the whole family	Family decision-making tool
Ethics consultant	Balancing benefits and burden	Map family values to treatment options
Chaplain	Incorporating religious and/or spiritual values	
	Emotional, grief support	

SIPAT, Stanford Integrated Psychosocial Assessment for Transplantation.

<sup>a</sup> Individual team members will differ on the basis of local resources, and any 1 member may offer multiple areas of expertise.

meets with the Bakers to hear about their experience of previous medical decisions for Hannah. He or she also reviews how parents can participate in serious medical decisions and outlines the full scope and intent of the TDSP.

Key information learned: The Bakers' previous decisions about Hannah's care seemed easy to them; they consented to surgical repair of the myelomeningocele and placement of the ventriculoperitoneal shunt because "she needed it." The decision about LTV seems less straightforward to them. The facilitator also uncovers some social complexities. The Bakers live in rural community 3 hours away from the only

children's hospital in the state. They lack reliable transportation and have difficulty securing time off from work to visit and participate in Hannah's care. They have a 3-year-old daughter. Their extended family lives too far away to help them out on a routine basis. The Bakers primary goal is for Hannah to come home. They do not know anything about the medical foster care system.

ICU case manager: The case manager reviews with the TDSP facilitator the initial information about the family's social context, and together, they go over with the family an adapted version of the Stanford Integrated Psychosocial Assessment for Transplantation

psychosocial evaluation.<sup>8</sup> The ICU case manager explores available pediatric home nursing, home medical equipment, and medical transportation options given the Bakers' home address and insurance benefits. He or she and the facilitator meet with the Bakers to discuss that information.

Key information learned: There is no pediatric home nursing available in the family's area; inquiries have been made to adult home nursing companies. The Bakers' home has inadequate electrical wiring to support the equipment necessary for LTV, so a local electrician is contacted to find out if safe rewiring is possible. A medical van can be arranged

for scheduled doctor's visits but not for other transportation. No medical day care is available in their county. There is no long-term care facility in the state for children on LTV.

Parent-representative videos: The Bakers receive a video with testimonials from 10 other families who have chosen for and against LTV that illustrates that there can be >1 choice to be made.

Parents who chose LTV: A mother talks about her 3-year old son who received a tracheostomy as an infant then spent 5 months in the PICU. Their house is described as a "mini ICU." Mother stopped working outside the home, and a home health nurse comes for 8 hours at night. There are related costs that insurance does not cover, although their church helps them with some financial difficulties. Her son has developmental delay, he smiles and is a valued part of the family but does not talk. She could not imagine having made a different decision.

Parents who did not choose LTV: A mother discusses how the doctors told her that her daughter would need LTV indefinitely. She and her partner initially disagreed with each other about LTV. As a mother, she hated to say that they should let her die. Ultimately, they did not want her "hooked up to machines" for life, so they pursued palliative care and her daughter died peacefully. Mother remarks that she still wishes her daughter could have gotten better, but she knows she made the right decision.

Home health nurse: The adult home health company that will be contracted for the Bakers, should Hannah receive LTV, arranges a home visit in conjunction with the palliative care nurse practitioner. Although this home health company does not traditionally deliver pediatric care, it is willing to consider expanding its services and hire pediatric nurses if able. The representative confirms that the home health nurse would be available overnight, but because of staff scheduling, the assigned nurse will not be consistent.

Key information learned: Because Hannah will not have her own bedroom, the home

health nurse describes how the family's living room might be adapted to accommodate her bed and medical equipment.

Palliative care nurse practitioner: The palliative care nurse practitioner conducts the home visit with the Bakers and their 3-year-old daughter, Emily. The nurse practitioner reviews the Seattle Children's Hospital Decision-Making Tool's 4 domains with the Bakers: (1) medical indications for treatment, (2) parent preferences, (3) quality of life, and (4) contextual issues.<sup>7</sup> He or she describes how these issues are important to health decisions for children and helps the Bakers review each domain for their daughter Hannah. He or she asks the Bakers if they want to know more about the option to decline LTV and pursue palliative care alone.

Key information learned: The Bakers' primary goal is for Hannah to come home and be a part of their family. They are worried about how they could care for her if she has LTV, especially with the many barriers identified.

TDSP facilitator: It takes 2 weeks for these TDSP activities to occur. Once the information is gathered, members of the TDSP convene and develop a recommendation. The facilitator joins the ICU attending currently caring for Hannah and the pulmonologist who would manage her long-term to meet with the Bakers regarding their decision about LTV for Hannah. During this discussion, the Bakers are given the opportunity to learn the TDSP team's recommendation.

## DISCUSSION

The TDSP, as described here, would incorporate individual interventions that have shown promise in other contexts into a comprehensive and formalized process. We are aware of no published data describing systematic approaches to making decisions like this. Alternatively, data from parents suggest that coordinated and comprehensive approaches to serious decisions, such as a tracheostomy and LTV, are not the norm.<sup>10,11</sup> Individual elements of the TDSP, such as clinical triggers,

structured family meetings, and decision tools for families, have each been shown to demonstrate value.<sup>7,12,13</sup> Local resources will shape the TDSP in each site, making some elements more or less viable. The home visit, for example, may be challenging to accomplish in some settings. Yet we suggest that valuable understanding could come from a home visit during which health care providers both gather and share understanding of how LTV would fit into a particular family's home environment. When this is not possible, some advantages of a home visit might be possible via technology (eg, joining a home health representative in a video conference with the family as they give a tour of their home), whereas other elements (the decision-making tool) could be incorporated into hospital discussions. Although clinicians at some sites may already be incorporating some aspects of the TDSP, we lack data about the impact on decisions, families, workflow, and cost. We are actively engaging in scientific evaluation of the TDSP with those goals.

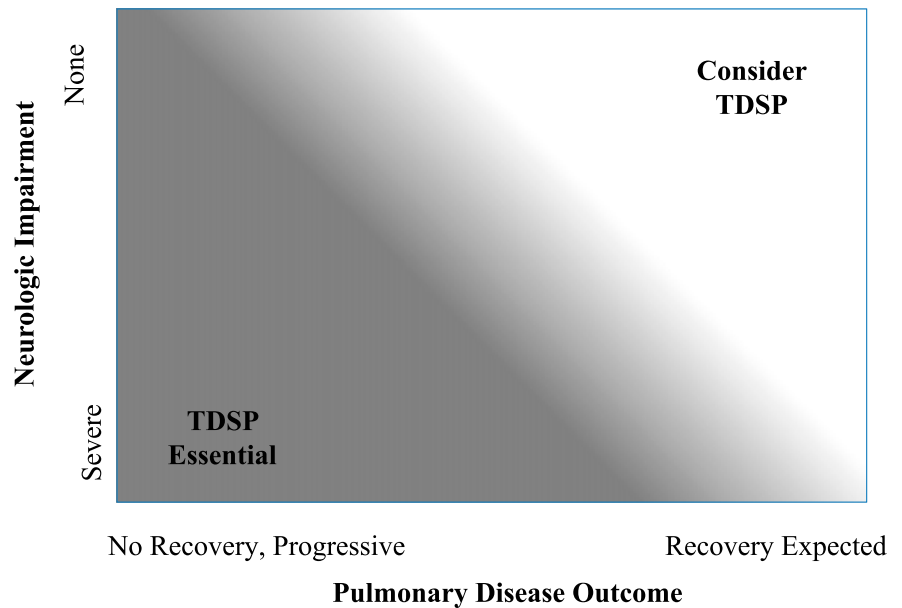
The goal of the proposed TDSP model is to help families formulate decisions about LTV on the basis of robust information regarding the lived experience of LTV for many families and, specifically, the predicted experience for their family. Although the principle value of the TDSP will likely be in the longitudinal process itself, allowing a family to thoroughly assimilate their social context and the potential medical needs of their child, a treatment recommendation from the TDSP team that incorporates the family's social context could be valuable to many families. The TDSP recommendation would stem from what has been heard from the family regarding their wishes, values, and goals for the child combined with the tangible knowledge of their social context. In weighing the factors that are relevant to the decision about LTV for an individual child, social context should receive equal consideration with the child's clinical factors.<sup>14</sup> Although a high-risk social context would not be sufficient to trump compelling clinical factors, it would be given serious attention. After the recommendation, the family would have time to deliberate and potentially disagree.<sup>15</sup> Given that the TDSP



began with clinician consensus regarding a range of reasonable treatment options to share with the family, the family's choice would be prioritized over the treatment recommendation. When conflict arises between the family's evaluation of their ability to provide the needed care for the child and the TDSP team's assessment of such, the usual clinical approaches would apply, including ongoing discussion, involvement of bioethics consultants, or involvement of Child Protective Services if appropriate.

Although clinicians may already incorporate aspects of TDSP when counseling families about advanced technologic support, a formalized, structured, and consistent process, such as the 1 we describe here, could be more robust and fair. The treatment alternatives will differ for children needing LTV for different reasons and durations (Fig 2); when decannulation is expected to occur fairly quickly, for instance, the TDSP may not bring added value to decision-making. On the other hand, for older children with deteriorating neurologic function but no current need for technology, elements of the TDSP could be initiated by the primary pediatrician or a hospitalist during a short admission for medication titration to begin to explore with the family the potential future decisions around technology. Helping each family consider how their social context is relevant to decisions about advanced technologies is consistent with a just and deliberative model of shared decision-making because it creates space for scrutiny and conflicting perceptions.<sup>16</sup> The TDSP could be an opportunity to expand decisions about LTV to include consideration of where that child is likely to spend his or her days and what that will be like for him or her and the entire family. The TDSP could also continue as a longitudinal resource for the family and their clinicians, enriching future deliberations, such as escalating or withdrawing from technologic support.

Although medical teams may not currently have an acknowledged role in incorporating family context into decisions about LTV, our experience is that medical teams are currently doing this in an ad hoc, idiosyncratic, implicit way. We advocate an



**FIGURE 2** Degree of neurologic and respiratory morbidities as indications for technology decision support process.

explicit, transparent, consistent approach that honors parents' authority to opt out of the TDSP and/or to refuse a TDSP recommendation. A timely and transparent system for social discussions can normalize the process and broaden its application. This conceptual approach could be adapted within a particular institutional framework and, using continuous process-improvement practices, assessed and modified to achieve its goals. Furthermore, prospective research will be essential to evaluating the impact of such an approach for families. Certainly, the TDSP cannot address the broader social disparities that impact the family capacity to care for a child with home technology; research that brings service gaps to light and advocacy aimed at expanding family supports must also occur. In the end, helping parents of the growing population of children with medical complexity, in whom social barriers loom large, can begin with deliberate conversations to bring those barriers into focus.

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