



Hospital Discharge of the High-Risk Neonate

Committee on Fetus and Newborn

Organizational Principles to Guide and Define the Child Health Care System and/or Improve the Health of All Children

ABSTRACT

This policy statement updates the guidelines on discharge of the high-risk neonate first published by the American Academy of Pediatrics in 1998. As with the earlier document, this statement is based, insofar as possible, on published, scientifically derived information. This updated statement incorporates new knowledge about risks and medical care of the high-risk neonate, the timing of discharge, and planning for care after discharge. It also refers to other American Academy of Pediatrics publications that are relevant to these issues. This statement draws on the previous classification of high-risk infants into 4 categories: (1) the preterm infant; (2) the infant with special health care needs or dependence on technology; (3) the infant at risk because of family issues; and (4) the infant with anticipated early death. The issues of deciding when discharge is appropriate, defining the specific needs for follow-up care, and the process of detailed discharge planning are addressed as they apply in general to all 4 categories; in addition, special attention is directed to the particular issues presented by the 4 individual categories. Recommendations are given to aid in deciding when discharge is appropriate and to ensure that all necessary care will be available and well coordinated after discharge. The need for individualized planning and physician judgment is emphasized. *Pediatrics* 2008;122:1119–1126

INTRODUCTION

The decision of when to discharge an infant from the hospital after a stay in the NICU is complex.¹ This decision is made primarily on the basis of the infant's medical status but is complicated by several factors. These factors include the readiness of families for discharge, differing opinions about what forms of care can be provided at home, and pressures to contain hospital costs by shortening the length of stay. Insofar as possible, determination of the readiness for discharge should be based on peer-reviewed scientific evidence. Shortening the length of a hospital stay may benefit the infant and family by decreasing the period of separation of infant and parents; moreover, the infant may benefit from shortening its exposure to the risks of hospital-acquired morbidity. However, the overriding concern is that infants may be placed at risk of increased mortality and morbidity by discharge before physiologic stability is established. Infants born preterm with low birth weight who require neonatal intensive care experience a much higher rate of hospital readmission and death during the first year after birth compared with healthy term infants.^{2–5} Careful preparation for discharge and good follow-up after discharge may reduce these risks. It takes time for the family of a high-risk infant to prepare to care for their infant in a home setting and to obtain the necessary support services and mobilize community resources. With increased survival of very preterm and very ill infants, many infants are discharged with unresolved medical issues that complicate their subsequent care. Infants are often discharged requiring more care and closer follow-up than was typical in the past. In addition, societal and economic forces have come to bear on the timing and process of discharge and follow-up care. As a result, health care professionals need guidance in assessing readiness for discharge and planning for subsequent care. This policy statement, therefore, addresses 4 broad categories of high-risk infants: (1) the preterm infant; (2) the infant with special health care needs or dependence on technology; (3) the infant at risk because of family issues; and (4) the infant with anticipated early death. This policy statement updates a previous guideline published by the American Academy of Pediatrics in 1998.¹

CATEGORIES OF HIGH-RISK INFANTS

The Preterm Infant

Historically, preterm infants were discharged only when they achieved a certain weight, typically 2000 g (5 lb). However, randomized clinical trials^{6–8} have shown that earlier discharge is possible without adverse health effects

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Key Words

discharge, high risk, premature, neonate, infant

Abbreviation

SIDS—sudden infant death syndrome
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when preterm infants are discharged on the basis of physiologic criteria rather than body weight. Although the population characteristics, the nature and results of the outcome measures, and the content of the early discharge programs in these studies varied, the common elements included:

- physiologic stability;
- an active program of parental involvement and preparation for care of the infant at home;
- arrangements for health care after discharge by a physician or other health care professional who is experienced in the care of high-risk infants; and
- an organized program of tracking and surveillance to monitor growth and development.

The 3 physiologic competencies that are generally recognized as essential before hospital discharge of the preterm infant are oral feeding sufficient to support appropriate growth, the ability to maintain normal body temperature in a home environment, and sufficiently mature respiratory control. These competencies are achieved by most preterm infants between 36 and 37 weeks' postmenstrual age,^{7,9} but maturation of respiratory control to a point that allows safe discharge may take longer, occasionally up to 44 weeks' postmenstrual age.^{10,11} Although interrelated, not all competencies are achieved by the same postnatal age in a given infant. The pace of maturation is influenced by the birth weight, the gestational age at birth, and the degree and chronicity of neonatal illnesses. Infants born earlier in gestation and with more complicated medical courses tend to take longer to achieve these physiologic competencies.

Home monitors are rarely indicated for detection of apnea solely because of immature respiratory control, in part because infants with immature respiratory control, in general, are still hospitalized until they are no longer at risk of apnea of prematurity. Use of a home monitor does not preclude the need for demonstrated maturity of respiratory control before discharge and should not be used to justify discharge of infants who are still at risk of apnea. Home monitors are not indicated for prevention of sudden infant death syndrome (SIDS) in preterm infants,¹² although preterm infants are at increased risk of SIDS.¹³ Formal laboratory analyses of breathing patterns (ie, "pneumograms") are of no value in predicting SIDS¹² and are not helpful in identifying patients who should be discharged with home monitors.

Preterm infants should be placed supine for sleeping,¹⁴⁻¹⁷ just as term infants should, and the parents of preterm infants should be counseled about the importance of supine sleeping in preventing SIDS. Hospitalized preterm infants should be kept predominantly in the supine position, at least from the postmenstrual age of 32 weeks onward, so that they become acclimated to supine sleeping before discharge. Supine positioning for sleep has led to an increase in positional skull deformity, especially in preterm infants but also in term infants^{16,18,19}; although only cosmetic, these deformities can be quite disturbing to parents. Ways of safely pre-

venting and treating deformation of the skull have been identified and are the subject of further investigation.^{15,18,20}

Late-preterm infants, those born between 34 and 37 weeks' gestation, are at increased risk of having feeding problems and hyperbilirubinemia after discharge. These problems can be minimized but not wholly prevented by careful discharge planning and close follow-up after discharge.²¹

The Infant With Special Health Care Needs or Dependence on Technology

In recent years, increasing numbers of children with unresolved medical problems or special health care needs have been discharged requiring some form of supportive technology.²² For newborn infants, the main types of technological support needed are nutritional support and respiratory support, including supplemental oxygen. This discussion will focus on nutritional and respiratory support, although other forms of home technological support are sometimes needed, including intravenous medications, bladder catheterization, and renal replacement therapy.

For most preterm infants and those with complex medical problems, oral feeding is best learned in the hospital under the care of expert physicians, nurses, and feeding therapists. Gavage feeding has been used safely in the home setting for infants who are not able to feed well enough by breast or bottle.²³⁻²⁵ This practice has a limited role and should be considered only when feeding is the last issue requiring continued hospitalization. Not all parents are capable of safely managing home gavage feedings. When little or no progress is being made with oral feeding skills and long-term tube feeding seems inevitable, placement of a feeding gastrostomy tube provides another alternative method of feeding.²⁶ Unless precluded by neurologic deficits that threaten airway defense, oral feeding should be continued along with tube feeding so that oral feeding skills can continue to develop. Ordinarily, gavage or gastrostomy tube feedings are used to complement what is eaten orally to ensure adequate total intake. Home intravenous nutritional support is sometimes needed when enteral feeding is not possible or is limited by short-bowel syndrome or poor gastrointestinal function. Parenteral nutrition in the home requires careful assessment of the caregivers and home environment, thorough education of caregivers, and the support of a well-qualified home-care company.²⁷

Home oxygen therapy for infants with bronchopulmonary dysplasia has been used as a means of achieving earlier hospital discharge while avoiding the risks of growth failure and cor pulmonale resulting from marginal oxygenation.²⁸⁻³³ Sufficient oxygen should be delivered to maintain oxygen saturation at an acceptable level during a range of activities.³⁴⁻³⁶ Infants who are discharged on supplemental oxygen are often also discharged on a cardiorespiratory monitor or pulse oximeter in case the oxygen should become dislodged or the supply depleted. Reducing or stopping supplemental oxygen should be supervised by the physician or other

health care professional and attempted only when the infant demonstrates normal oxygen saturation, good growth velocity, and sufficient stamina for a full range of activity.³⁶ Tracheostomy is sometimes required for neonates with upper airway abnormalities or occasionally for infants who cannot be weaned from assisted ventilation.^{37–40} Good parental teaching and coordinated multidisciplinary follow-up care are essential for these infants. Infants who require home ventilation should also be on a cardiorespiratory monitor in case the airway should become obstructed, but the home ventilator should also have a disconnect alarm to alert caregivers to ventilator disconnection. Home ventilation requires qualified personnel to provide bedside care; in most cases, home-nursing support will be needed for at least part of the day.

The Infant at Risk Because of Family Issues

Preterm birth and prolonged hospitalization are known family stressors and risk factors for subsequent family dysfunction and child abuse.^{41–43} In addition to preterm birth and prolonged hospital stay, birth defects and disabling conditions are also risk factors.⁴⁴ Maternal factors include lower educational level, lack of social support, marital instability, and fewer prenatal care visits.^{41,42} In 1 study, significantly fewer family visits during the stay in the NICU had occurred for infants in whom subsequent maltreatment was documented.⁴¹ Parental substance abuse is another factor that places the infant at risk, both because of adverse effects on the developing fetus in utero and because of possible postnatal exposure to drugs through breastfeeding or by inhalation. Moreover, the drug-seeking behaviors of parents may compromise the safety of the child's environment. Sequelae such as attachment disturbances, behavioral and developmental disorders, and child maltreatment have been observed frequently among children born to substance abusers.

Identifying effective strategies to help protect the infant who is at increased risk because of family reasons has been elusive. Most interventions have focused on multidisciplinary teams that provide follow-up monitoring, including home visits.⁴⁵ However, the efficacy of these interventions has been difficult to demonstrate. At the very least, it is hoped that an organized approach to planning for discharge can identify infants who require extra support or whose home environments present unacceptable risks.

The Infant With Anticipated Early Death

For many infants with incurable, terminal disorders, the best place to spend the last days or weeks of life is at home.⁴⁶ In these situations, the family provides most of the care, often with support by staff from a community hospice organization. In rare instances, withdrawal of assisted ventilation can occur in the home.⁴⁷ In preparing to discharge an infant for home hospice care, several aspects must be considered in addition to the usual factors.⁴⁸ These preparations include arrangements for medical follow-up and home-nursing visits; management of pain and other distressing symptoms; arrange-

ments for home oxygen or other equipment and supplies; providing the family with information on bereavement support for the parents, siblings, and others; discussion of possible resources for respite of caregivers; and assistance in addressing financial issues. If appropriate, a letter should be provided for the family to show to other caregivers or emergency medical workers indicating that the child should not be resuscitated. The focus of planning efforts should be to enhance the quality of the infant's remaining life for the benefit of both the infant and his or her family.

TIMING OF DISCHARGE

The appropriate time for discharge is when the infant demonstrates the necessary physiologic maturity (in the case of the preterm infant), discharge planning and arrangements for follow-up and any home care have been completed, and the parents have received the necessary teaching and have demonstrated their mastery of the essential knowledge and skills. In selected cases, an infant may be discharged before one of the infant's physiologic competencies has been met, provided the health care team and the parents agree that this is appropriate and suitable plans have been made to provide additional support needed to ensure safe care at home, such as tube feeding, cardiorespiratory monitoring, or home oxygen. The standard, default criterion remains that the infant should be sufficiently mature to need no such assistance at home. The decision to facilitate earlier discharge by providing such additional support should be made only as a mutual decision by the health care team and the parents.

Before discharge, the eyes of qualifying infants should be examined at specified times by an ophthalmologist with expertise in the diagnosis of retinopathy of prematurity.⁴⁹ The infant's hearing should be evaluated^{50,51}; the results of the newborn metabolic screen should be reviewed⁵²; appropriate immunizations should be given, if not given previously; and palivizumab should be given to qualifying infants during respiratory syncytial virus season.^{53,54}

Sometimes infants are transferred to a hospital closer to home so that the family may visit more easily. This is appropriate provided appropriate medical care is available in the receiving hospital, including capabilities for ophthalmologic examinations to screen for retinopathy of prematurity and the experience and resources for planning discharge and follow-up care.

DISCHARGE PLANNING

High-risk infants should receive primary medical care from a physician with expertise in the care of patients who have spent time in the NICU, often in partnership with 1 or more specialized clinics in the discharging medical center. To ensure continuity of care after discharge, infants with unresolved medical issues that persist after their hospital stay, such as bronchopulmonary dysplasia or feeding dysfunction, should be comanaged by a neonatologist or other medical subspecialist from the hospital at which most of the care was provided. The

subspecialist provides consultation to the primary physician about issues such as the weaning and discontinuation of supplemental oxygen. Most high-risk infants should also be enrolled in a follow-up clinic that specializes in the neurodevelopmental assessment of high-risk infants. This neurodevelopmental follow-up is sometimes integrated with the child's visits to the neonatologist. Standardized assessments should be performed in the follow-up clinic at specific ages through early childhood.⁵⁵⁻⁵⁷

The care of each high-risk neonate after discharge must be coordinated carefully to provide ongoing multidisciplinary support of the family. The discharge-planning team should include parents, the neonatologist, neonatal nurses and nurse practitioners, and the social worker. Other professionals, such as surgical specialists and pediatric medical subspecialists, respiratory, physical, occupational, and speech therapists, infant educators, nutritionists, home-health care company staff, and others may be included as needed.

Discharge planning should begin early in the hospital course. The goal of the discharge plan is to ensure successful transition to home care. Essential discharge criteria are a physiologically stable infant, a family who can provide the necessary care with appropriate support services in the community, and a primary care physician who is prepared to assume the responsibility with appropriate backup from specialist physicians and other professionals as needed.^{55,56} Six critical components must be included in discharge planning.

1. Parental Education

Parental contact and involvement in the care of the infant should be encouraged from the time of admission. The participation of the parents in whatever way possible from the beginning has a positive effect on their confidence in handling the infant and readiness to assume full responsibility for the infant's care at home.

The development of an individualized teaching plan helps parents to acquire the skills and judgment needed to care for their infant. A written checklist or outline of the specific areas and tasks to be mastered increases the likelihood that parents and other caregivers will receive complete instructions and experience. Caregivers and parents must understand that the infant's immaturity and medical status will require increased care and vigilance at home beyond that of the usual parental role. Thus, ample time for teaching the parents and caregivers the techniques and the rationale for each item in the care plan is essential. Requesting return demonstrations by the parents of their new knowledge, parent rooming-in, and telephone follow-up by hospital staff all facilitate parental education and adaptation to their infant's care. Although it is important for the parents to understand that their child may need extra care and surveillance, the infant's fragility should not be overstated. If this occurs, the parents may become excessively protective, which can restrict the child's social development and lead to behavior problems.⁵⁸ Parents should be coached in communicating about the infant with any older siblings, who may not fully understand the infant's condition and may

even imagine themselves to be responsible for the vulnerable state of their younger brother or sister.

Insofar as possible, at least 2 responsible caregivers should be identified and learn the necessary care for each infant. The demands of home care can be physically and emotionally draining, especially at first, for infants who require frequent feeding. Young mothers who do not live with a parent or the father of the infant have been shown to be especially vulnerable to the strains of home care. Even in a 2-parent family, the primary caregiver may become ill and need relief.

2. Completion of Appropriate Elements of Primary Care in the Hospital

Preparing the infant for transition to primary care begins early in the hospitalization with administration of immunizations at the recommended postnatal ages, regardless of prematurity or medical condition,⁵⁹ completion of metabolic screening,⁵² assessment of hearing by an acceptable electronic measurement,^{50,51} and baseline neurodevelopmental and neurobehavioral assessment. For infants at risk, appropriate fundoscopic examination for retinopathy of prematurity should be performed by an ophthalmologist who is skilled in the evaluation of the retina of the preterm infant.⁴⁹ Assessment of hematologic status is recommended for all infants because of the high prevalence of anemia after neonatal intensive care. Very preterm infants and those who have received parenteral nutrition for prolonged periods may be at risk of hypoproteinemia, vitamin deficiencies, and bone mineralization abnormalities; therefore, evaluation for nutritional or metabolic deficiencies may be indicated. When discharge is near, the high-risk infant should be evaluated to ensure physiologic stability in an appropriate car seat or car bed.⁶⁰⁻⁶²

3. Development of Management Plan for Unresolved Medical Problems

Review of the hospital course and the active problem list of each infant and careful physical assessment will reveal any unresolved medical issues and areas of physiologic function that have not reached full maturation. From such a review, the diagnostic studies required to document the current clinical status of the infant can be identified and management can be continued or adjusted as appropriate. The intent should be to ensure implementation of appropriate home-care and follow-up plans.

4. Development of the Comprehensive Home-Care Plan

Although the content of the home-care plan may vary with the infant's diagnoses and medical status, the common elements include (1) identification and preparation of the in-home caregivers, (2) formulation of a plan for nutritional care and administration of any required medications, (3) development of a list of required equipment and supplies and accessible sources, (4) identification and mobilization of the primary care physician, the necessary and qualified home-care personnel and community support services, (5) assessment of the adequacy of the physical facilities within the home, (6) development

of an emergency care and transport plan, and (7) assessment of available financial resources to ensure the capability to finance home-care costs. The input of the primary care physician in formulating the home-care plan of the technology-dependent infant is essential. Many infants, particularly extremely preterm and technology-dependent infants, require continued care by multiple specialists and subspecialists, who should be included in the predischarge assessment and discharge planning.

5. Identification and Involvement of Support Services

The infant's optimal outcome ultimately depends on the capacity and effort of the family. The psychological, social, economic, and educational condition and needs of the family should be addressed from the beginning of the infant's hospitalization, noting strengths that can support the infant's continued adaptation, growth, and development and any risk factors that may contribute to an adverse infant outcome. The availability of social support is essential for the success of every parent's adaptation to the home care of a high-risk infant. Before discharge and periodically thereafter, a review of the family's needs, coping skills, use of available resources, financial problems, and progress toward goals in the home care of their infant should be evaluated. After the social support needs of the family have been identified, an appropriate, individualized intervention plan using available community programs, surveillance, or alternative care placement of the child may be implemented.

6. Determination and Designation of Follow-Up Care

In general, the attending neonatologist or other discharging physician has the responsibility for coordination of follow-up care, although in some institutions this responsibility may be delegated to another professional. A primary care physician (or "medical home") should be identified well before discharge to facilitate the coordination of follow-up care planning between the staff responsible for planning the discharge and the primary health care professionals. Pertinent information about the nursery course, including a discharge summary, and the home-care plan should be given to the primary care physician before the infant's discharge. In specialty center units, the primary care attending physician should work with the neonatologist in coordinating the discharge planning.

Arrangements for an initial appointment with the primary care physician should be made before discharge. Specific follow-up appointments with each involved surgical specialist and pediatric medical subspecialist should be made, giving attention to grouping the appointments as much as possible for the convenience of the family. A plan should be developed and discussed for emergency care and transportation to a hospital, should it be necessary.

Periodic evaluation of the developmental progress of every infant is essential for identifying deviations in neurodevelopmental progress at the earliest possible point, thereby facilitating entry into early interven-

tion programs. The primary care physician with appropriate skills, the pediatric medical subspecialist, or clinic personnel may provide longitudinal developmental follow-up. When need for input from multiple disciplines is identified before discharge, a clinic that provides multidisciplinary care, usually in an academic or tertiary center, may be the least cumbersome option for the family.

SPECIAL CONSIDERATIONS

Many infants are transported to hospitals nearer to their family homes for convalescent care. In these hospitals, the discharge-planning process should follow the same principles as those outlined previously in this statement for an infant being discharged from a subspecialty center. It is especially important that periodic examination by a qualified ophthalmologist be available for infants who still require evaluation for retinopathy of prematurity.

In caring for the discharged high-risk infant, use of community resources, both public and private, should be encouraged. The goal should be to provide coordinated care and family support. Efficient teamwork by health care professionals is imperative. Home-nursing visits are often indicated. When this is so, it is important to use experienced nurses who are qualified to perform the required assessments. When choosing a home-care company or agency for technology-dependent infants, it is essential that previous performance and existing quality-control programs be considered.

RECOMMENDATIONS

The following recommendations are offered as a framework for guiding decisions about the timing of discharge. It is prudent for each institution to establish guidelines that ensure a consistent approach yet allow some flexibility on the basis of physician and family judgment. It is of foremost importance that the infant, family, and community be prepared for the infant to be safely cared for outside the hospital.

Infant Readiness for Hospital Discharge

The infant is considered ready for discharge if, in the judgment of the responsible physician, the following have been accomplished:

- A sustained pattern of weight gain of sufficient duration has been demonstrated.
- The infant has demonstrated adequate maintenance of normal body temperature fully clothed in an open bed with normal ambient temperature (20–25°C).
- The infant has established competent feeding by breast or bottle without cardiorespiratory compromise.
- Physiologically mature and stable cardiorespiratory function has been documented for a sufficient duration.
- Appropriate immunizations have been administered.
- Appropriate metabolic screening has been performed.

- Hematologic status has been assessed and appropriate therapy has been instituted, if indicated.
- Nutritional risks have been assessed and therapy and dietary modification has been instituted, if indicated.
- Hearing evaluation has been completed.
- Funduscopic examinations have been completed, as indicated.
- Neurodevelopmental and neurobehavioral status has been assessed and demonstrated to the parents.
- Car seat evaluation has been completed.
- Review of the hospital course has been completed, unresolved medical problems have been identified, and plans for follow-up monitoring and treatment have been instituted.
- An individualized home-care plan has been developed with input from all appropriate disciplines.

Family and Home Environmental Readiness

Assessment of the family's caregiving capabilities, resource availability, and home physical facilities has been completed as follows:

- identification of at least 2 family caregivers and assessment of their ability, availability, and commitment;
- psychosocial assessment for parenting strengths and risks;
- a home environmental assessment that may include on-site evaluation; and
- review of available financial resources and identification of adequate financial support.

In preparation for home care of the technology-dependent infant, it is essential to complete an assessment documenting availability of 24-hour telephone access, electricity, safe in-house water supply, and adequate heating. Detailed financial assessment and planning are also essential. Parents and caregivers should have demonstrated the necessary capabilities to provide all components of care, including:

- feeding, whether by breast, bottle, or an alternative technique, including formula preparation, if required;
- basic infant care, including bathing; skin, cord, and genital care; temperature measurement; dressing; and comforting;
- infant cardiopulmonary resuscitation and emergency intervention;
- assessment of clinical status, including understanding and detection of the general early signs and symptoms of illness as well as the signs and symptoms specific to the infant's condition;
- infant safety precautions, including proper infant positioning during sleep and proper use of car seats or car bed;
- specific safety precautions for the artificial airway, if any; feeding tube; intestinal stoma; infusion pump;

and other mechanical and prosthetic devices, as indicated;

- administration of medications, specifically proper storage, dosage, timing, and administration and recognition of potential signs of toxicity;
- equipment operation, maintenance, and problem solving for each mechanical support device required; and
- the appropriate technique for each special care procedure required, including special dressings for infusion entry site, intestinal stoma, or healing wounds; maintenance of an artificial airway; oropharyngeal and tracheal suctioning; and physical therapy, as indicated.

Specific modification of home facilities must have been completed if needed to accommodate home-care systems. Plans must be in place for responding to loss of electrical power, heat, or water and for emergency relocation mandated by natural disaster.

Community and Health Care System Readiness

An emergency intervention and transportation plan have been developed and emergency medical services providers have been identified and notified, if indicated.

Follow-up care needs have been determined, appropriate providers have been identified, and appropriate information has been exchanged, including the following:

- A primary care physician has been identified and has accepted responsibility for care of the infant.
- Surgical specialty and pediatric medical subspecialty follow-up care requirements have been identified and appropriate arrangements have been made.
- Neurodevelopmental follow-up requirements have been identified and appropriate referrals have been made.
- Home-nursing visits for assessment and parent support have been arranged, as indicated by the complexity of the infant's clinical status and family capability, and the home-care plan has been transmitted to the home health agency.
- For breastfeeding mothers, information on breastfeeding support and availability of lactation counselors has been provided.

The determination of readiness for care at home of an infant after neonatal intensive care is complex. Careful balancing of infant safety and well-being with family needs and capabilities is required while giving consideration to the availability and adequacy of community resources and support services. The final decision for discharge, which is the responsibility of the attending physician, must be tailored to the unique constellation of issues posed by each infant's situation.

COMMITTEE ON FETUS AND NEWBORN, 2007–2008

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Neonatal Nurses

STAFF

Jim Couto, MA

*Lead author

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