

SHARED DECISION-MAKING OVERVIEW

	Goals of Care	Professionals Involved	Resources	Parental Consideration	Professional Considerations
Prenatal Diagnosis	<ul style="list-style-type: none"> - Determine if patient desires more information via ultrasound, amniocentesis, etc. - Determine if pregnancy will be continued - If yes, determine parent goals (Hold a live baby?, Take their baby home? Prolong survival?) - Acknowledge that goals may change - Discuss continuation of antenatal care and options for antenatal testing - Anticipate labor and delivery decisions, including fetal monitoring and route of delivery 	<ul style="list-style-type: none"> - Obstetrician - Maternal-Fetal Medicine - Genetic counselor - Neonatologist - Newborn NP/MD - Nurse - Consider: Perinatal hospice Pediatric subspecialists - CMH Case Managers 	<ul style="list-style-type: none"> - Spiritual support - Professional organizations - Support organizations, for example, SOFT - Web resources - Care after perinatal loss (mementos, photos, autopsy, genetic counseling) - See "Decision-making with families" resource 	<p>Experiences:</p> <ul style="list-style-type: none"> - Denial, Guilt, Anger - Powerlessness - Conflicted feelings (fear child dies, fear child lives, profound love) - Sadness (loss of expected child, baby cannot come home as assumed) <p>Other:</p> <ul style="list-style-type: none"> - Make sure families know that some infants survive days, months or years - Alleviate feelings of maternal guilt 	<ul style="list-style-type: none"> - Use the child's name <p><i>Professional challenges:</i></p> <ul style="list-style-type: none"> - Concern about time constraints - Lack of training in delivering difficult news - Confusion about roles of providers - Use of appropriate language - Conflicting values - Identify community-based palliative care or hospice resources and make referral - Avoid passing judgment
Labor and Delivery	<ul style="list-style-type: none"> - Plan for serial conversations - Promote interdisciplinary care - Define terminology carefully - Describe and discuss resuscitation scenarios and family wishes 	<ul style="list-style-type: none"> - Obstetrician/MFM - Neonatologist - Newborn NP/MD - Chaplain - Social work - Nurse 	<ul style="list-style-type: none"> - Care conference prior to delivery with development of a written care plan - See "Decision-making with families" resource 	<p>Fears:</p> <ul style="list-style-type: none"> - Facing uncertain future - Being misunderstood, judged - Sharing diagnosis with child's siblings, other family, friends - Anticipating abandonment at any stage of the pathway <p>Other:</p> <ul style="list-style-type: none"> - Make sure families know that some infants survive days, months or years - Alleviate feelings of maternal guilt 	<ul style="list-style-type: none"> - Use the child's name - Offer hope* - Ask "What do you need?" <p><i>Professional challenges:</i></p> <ul style="list-style-type: none"> - Personal preferences different from parents - Pressure to make the correct diagnosis in a timely fashion - Need to maintain both objectivity and empathy - Professional sense of failure and grief - Admit uncertainty - Importance of language - Avoid passing judgment

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Postnatal diagnosis	<ul style="list-style-type: none"> - Promote bonding with newborn - Deliver information in a timely manner that is easily understood - Initiate a preliminary discussion before final diagnosis, to allow for appropriate timing for processing of information - Explain what is likely to happen if: <ul style="list-style-type: none"> medical intervention is directed at comfort care simple, minimally invasive care is started more complex interventions are initiated - Inform family of further choices that are likely to arise in next days, weeks 	<ul style="list-style-type: none"> - Nurse - Obstetrician/MFM - Neonatologist - Newborn NP/MD - Chaplain - Supportive Care Team** - Medical Geneticist 	<ul style="list-style-type: none"> - Training on delivering difficult news - Care after neonatal loss (mementos, photos, autopsy, genetic counseling) - Support group contact information - See "Decision-making with familis" resource 	<p>Hopes and Desires:</p> <ul style="list-style-type: none"> - Acknowledgment of complexity of the experience - Parental need for accurate, complete, information on syndrome combined with willingness to let baby "write her own book" - Being heard on delivery preferences, especially C-section - Respected as any parents in the process of prenatal care and delivery - Consulted regarding balance of joyful/somber atmosphere at delivery - Allotted time to balance processing information with need for more 	<p>Suggested Strategies:</p> <ul style="list-style-type: none"> - Use the child's name - Recognize shock and disbelief - Be aware of the importance of culture - Use language that neither over nor under estimates family's abilities - Ask about parents' own hopes and fears - Admit uncertainty; offer hope - Ask "What do you need?" <p><i>Professional challenges:</i></p> <ul style="list-style-type: none"> - Avoid passing judgment
Neonatal Care	<ul style="list-style-type: none"> - Discuss discharge criteria - Clarify plans for fluids, nutrition, respiratory support resuscitation status - Explain what is likely to happen if: <ul style="list-style-type: none"> medical intervention is directed at comfort care simple, minimally invasive care is started more complex interventions are initiated - Consider Supportive Care Team** - Inform family of further choices that are likely to arise in next days, weeks - Write description of plan and clarify before D/C - Document plans in Medical Record - Promote care conferences, flexibility in decision-making, evolution of plans - Avoid temptation to make definitive plans too far into the future 	<ul style="list-style-type: none"> - Nurse - Primary care provider - Relevant subspecialists - Clinical social worker - Case manager - Supportive Care Team** - Home care provider - Medical Geneticist - Chaplain 	<ul style="list-style-type: none"> - Supportive Care Team** - Support groups - Home care RNs, therapists, agencies - Insurance/case management support - See "Decision-making with familis" resource 	<ul style="list-style-type: none"> - Encouraged to spend as much time with baby as possible - Respect for family spiritual preferences - Guided through changes in parental decisions at each decision point - Elimination of terms such as "vegetative," "lethal," "quality of life," "incompatible with life" - Appreciated feelings that baby is a loved, valued child, not a diagnosis - Being accepted without labels 	<ul style="list-style-type: none"> - Use the child's name - Describe organ malformations and normal organs using plain language - Work to integrate values and facts - Anticipate changes in decisions - Speak with extended families, if requested - Commit to having serial conversations - Reassure that the relationship continues - Prepare the family for the baby's appearance - Admit uncertainty; offer hope* - Ask "What do you need?" <p><i>Professional challenges:</i></p> <ul style="list-style-type: none"> - Avoid passing judgment

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D/C to home	<ul style="list-style-type: none"> - Provide supportive care to providers and families - Anticipate parents changing goals and plans - Inform family of further choices that are likely to arise in next days, weeks - Write a thorough plan including DNR orders in EMR, and with family - Clarify plan before discharge - Document plan in EMR 	<ul style="list-style-type: none"> - Supportive Care Team** - Family's spiritual support, for example, chaplain - Geneticists, other specialists - Home nurses - Therapist 	<ul style="list-style-type: none"> - Proactive support in finding hospital and physician support - Support groups in place - Ancillary care in place - Financial advice and support - Community hospital provider may need subspecialty support - See "Decision-making with familis" resource 	<ul style="list-style-type: none"> - Encouraged to spend as much time with baby as possible - Respect for family spiritual preferences - Guided through changes in parental decisions at each decision point - Elimination of terms such as "vegetative," "lethal," "quality of life," "incompatible with life" - Appreciated feelings that baby is a loved, valued child, not a diagnosis - Being accepted without labels 	<ul style="list-style-type: none"> - Admit uncertainty; offer hope - Ask "What do you need?" - Consider support for siblings

Adapted from Andrews, et al. Am J Med Gen 172C:257, 2016
and Janvier, et al. Pediatrics, 2012

*Hope for a liveborn infant, hope for discharge, hope for minimal suffering, hope for longer than expected survival, etc

**Suggested language to use with family: "The Children's Supportive Care Team is available to see any child with a serious illness who receives medical care at the UNC Children's Hospital. The team partners with you and your child's other medical providers to help understand your goals and wishes for your child, and also your worries and concerns as you care for your child and learn more about her/his medical condition and any symptoms s/he is experiencing . The team can help identify resources at the UNC Children's Hospital and in your home community that may be helpful as you continue to care for your child and make decisions about her/his medical care."