## SHARED DECISION-MAKING OVERVIEW

<table>
<thead>
<tr>
<th>Goals of Care</th>
<th>Professionals Involved</th>
<th>Resources</th>
<th>Parental Consideration</th>
<th>Professional Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Determine if patient desires more information via ultrasound, amniocentesis, etc.</td>
<td>Obstetrician</td>
<td>Spiritual support</td>
<td>Experiences:</td>
<td>- Use the child's name</td>
</tr>
<tr>
<td>Determine if pregnancy will be continued</td>
<td>Maternal-Fetal Medicine</td>
<td>Professional organizations</td>
<td>- Denial, Guilt, Anger</td>
<td>Professional challenges:</td>
</tr>
<tr>
<td>If yes, determine parent goals (Hold a live baby?, Take their baby home? Prolong survival?)</td>
<td>Genetic counselor</td>
<td>Support organizations, for example, SOFT</td>
<td>- Powerlessness</td>
<td>- Concern about time constraints</td>
</tr>
<tr>
<td>Acknowledge that goals may change</td>
<td>Neonatologist</td>
<td>Web resources</td>
<td>- Conflicted feelings (fear child dies, fear child lives, profound love)</td>
<td>- Lack of training in delivering difficult news</td>
</tr>
<tr>
<td>Discuss continuation of antenatal care and options for antenatal testing</td>
<td>Newborn NP/MD</td>
<td>Care after perinatal loss</td>
<td>- Sadness (loss of expected child, baby cannot come home as assumed)</td>
<td>- Confusion about roles of providers</td>
</tr>
<tr>
<td>Anticipate labor and delivery decisions, including fetal monitoring and route of delivery</td>
<td>Nurse</td>
<td>Mementos, photos, autopsy, genetic counseling</td>
<td>Other:</td>
<td>- Use of appropriate language</td>
</tr>
<tr>
<td></td>
<td>Consider: Perinatal hospice</td>
<td></td>
<td>- Make sure families know that some infants survive days, months or years</td>
<td>- Conflicting values</td>
</tr>
<tr>
<td></td>
<td>Pediatric subspecialists</td>
<td></td>
<td>- Alleviate feelings of maternal guilt</td>
<td>- Identify community-based palliative care or hospice resources and make referral</td>
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<tr>
<td></td>
<td>- CMIH Case Managers</td>
<td></td>
<td></td>
<td>- Avoid passing judgment</td>
</tr>
<tr>
<td>Plan for serial conversations</td>
<td>Obstetrician/MFM</td>
<td>Care conference prior to delivery with development of a written care plan</td>
<td>Fears:</td>
<td>Use the child's name</td>
</tr>
<tr>
<td>Promote interdisciplinary care</td>
<td>Neonatologist</td>
<td></td>
<td>- Facing uncertain future</td>
<td>Offer hope*</td>
</tr>
<tr>
<td>Define terminology carefully</td>
<td>Newborn NP/MD</td>
<td>- See &quot;Decision-making with families&quot; resource</td>
<td>- Being misunderstood, judged</td>
<td>Ask &quot;What do you need?&quot;</td>
</tr>
<tr>
<td>Describe and discuss resuscitation scenarios and family wishes</td>
<td>Chaplain</td>
<td></td>
<td>- Sharing diagnosis with child's siblings, other family, friends</td>
<td>Professional challenges:</td>
</tr>
<tr>
<td></td>
<td>Social work</td>
<td></td>
<td>- Anticipating abandonment at any stage of the pathway</td>
<td>- Personal preferences different from parents</td>
</tr>
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<td></td>
<td>Nurse</td>
<td></td>
<td>Other:</td>
<td>- Pressure to make the correct diagnosis in a timely fashion</td>
</tr>
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<td></td>
<td>- CMIH Case Managers</td>
<td></td>
<td>- Make sure families know that some infants survive days, months or years</td>
<td>- Need to maintain both objectivity and empathy</td>
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<td></td>
<td>- See &quot;Decision-making with families&quot; resource</td>
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<td>- Alleviate feelings of maternal guilt</td>
<td>- Professional sense of failure and grief</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>- Admit uncertainty</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>Importance of language</td>
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<tr>
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<td></td>
<td>Avoid passing judgment</td>
</tr>
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### Goals of Care
- 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: 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

### Professionals Involved
- Nurse
- Obstetrician/MFM
- Neonatologist
- Newborn NP/MD
- Chaplain
- Supportive Care Team**
- Medical Geneticist

### Resources
- Training on delivering difficult news
- Care after neonatal loss (mementos, photos, autopsy, genetic counseling)
- Support group contact information
- See "Decision-making with familis" resource

### Parental Consideration
- Hopes and Desires:
- 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

### Professional Considerations
- Suggested Strategies:
  - 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?"

- Professional challenges:
  - Avoid passing judgment

### Postnatal diagnosis

### Neonatal Care
- Discuss discharge criteria
- Clarify plans for fluids, nutrition, respiratory support resuscitation status
- Explain what is likely to happen if: 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

### Professionals Involved
- Nurse
- Primary care provider
- Relevant subspecialists
- Clinical social worker
- Case manager
- Supportive Care Team**
- Home care provider
- Medical Geneticist
- Chaplain
- Supportive Care Team**

### Resources
- Support groups
- Home care RNs, therapists, agencies
- Insurance/case management support
- See "Decision-making with familis" resource

### Parental Consideration
- 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

### Professional Considerations
- 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?*

**Professional challenges:**
- Avoid passing judgment
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<td>Provide supportive care to providers and families</td>
<td>– Supportive Care Team**</td>
<td>– Proactive support in finding hospital and physician support</td>
<td>– Encouraged to spend as much time with baby as possible</td>
<td>– Admit uncertainty; offer hope</td>
</tr>
<tr>
<td>Anticipate parents changing goals and plans</td>
<td>– Family’s spiritual support, for example, chaplain</td>
<td>– Support groups in place</td>
<td>– Respect for family spiritual preferences</td>
<td>– Ask “What do you need?”</td>
</tr>
<tr>
<td>Inform family of further choices that are likely to arise in next days, weeks</td>
<td>– Geneticists, other specialists</td>
<td>– Ancillary care in place</td>
<td>– Guided through changes in parental decisions at each decision point</td>
<td>– Consider support for siblings</td>
</tr>
<tr>
<td>Write a thorough plan including DNR orders in EMR, and with family</td>
<td>– Home nurses</td>
<td>– Financial advice and support</td>
<td>– Elimination of terms such as “vegetative,” “lethal,” “quality of life,” “incompatible with life”</td>
<td></td>
</tr>
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<td>Clarify plan before discharge</td>
<td>– Therapist</td>
<td>– Community hospital provider may need subspecialty support</td>
<td>– Appreciated feelings that baby is a loved, valued child, not a diagnosis</td>
<td></td>
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<td>Document plan in EMR</td>
<td></td>
<td>– See “Decision-making with familis” resource</td>
<td>– Being accepted without labels</td>
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*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.”**