# Neonatal Ethics Teaching Program

## Scenario Oriented Learning in Ethics (SOLE)

## Announcing the Diagnosis of Trisomy 21

### Trainee Guide

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Last revised: May 11, 2018

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## Description of SOLE Workshop

Delivering unexpected news to patients and their families can lead to emotionally charged conversations that are difficult for trainees to feel comfortable or effective in. Trisomy 21 (T21), or Down syndrome, is the most common viable chromosomal anomaly. Although prenatal screening exists, over 80% of T21 diagnoses continue to be made postnatally to unsuspecting parents who report a desire for better communication from healthcare professionals when they first receive the news of their child's diagnosis.[16]

To better equip trainees to thoughtfully and professionally deliver a diagnosis of T21, we have designed a workshop founded on the principles of Scenario Oriented Learning in Ethics (SOLE) which introduces a framework combining current evidence on communicating life altering news with stated parent preferences. During the workshop, trainees will have the opportunity to practice using the provided communication framework with a standardized patient trained as a new mother. By personally working through a clinical scenario as well as observing workshop colleagues doing the same, participants will gain insight into what is effective as well as ways to troubleshoot encountered pitfalls in a safe and supportive environment. By pre-emptively practicing evidence-based communication, we hope to increase trainee comfort with critical conversations and improve parents' feelings regarding the quality of communication and support provided while receiving real life T21 diagnoses.

## Objectives

1. Inform families of a T21 diagnosis in manner that is sensitive to their cultural, social, and religious backgrounds.
2. Recognize and validate a variety of emotional reactions even if they are not shared.
3. Utilize current evidence to explain T21 in a practical and tangible manner.
4. Incorporate shared decision making into a focused evidence based management plan

## How to Prepare for this SOLE

1. Read the required readings.
2. Review the evidence on to improve delivery of T21 diagnosis (see Appendix A)
3. Read, in detail, the case scenario involving the standardized patient (see Appendix B)
4. Review, in detail, the suggested communication strategies outlined in the provided communication framework (see Appendix C).
5. Read the summary sheet entitled "Knowledge Based Principles" that addresses common questions parents may have related to T21 (see Appendix D)

## Required Reading


- Bull, M., & the Committee on Genetics. (2011). Clinical Report - Health Supervision for Children with Down Syndrome. *Pediatrics*. 128(2), 393-406.
- Koh, H.K., & Rudd, R.E. (2015). The Arc of Health Literacy. *JAMA, 314(12),* 1225 - 1226.
- Skotko, B., Capone, G., & Kishnani, P. (2009). Postnatal Diagnosis of Down Syndrome: Synthesis of the Evidence on How Best to Deliver the News. *Pediatrics*. 124, e751.


## Additional References (non-mandatory)


- Hobson-Rohrer, W., & Samson-Fang, L. (2013). Down Syndrome. *Pediatrics in Review*. 34, 573-574. DOI: 10.1542/pir.34-12-573
- Hedov, G., Wikblad, K., & Annerén, G. (2002). First information and support provided to parents of children with Down syndrome in Sweden: clinical goals and parental experiences. *Acta Paediatrica (Oslo, Norway: 1992), 91*(12), 1344–1349.


## SOLE Workshop Timeline

**Introduction (15 min)**

1) Pre-briefing between trainees and supervisor to outline workshop goals
2) Answering of questions to clarify the strategies for delivering a diagnosis of a T21 (trainees and supervisors)

**Practice with the Standardized Patient (80 min)**

1) 25 min to cover the initial steps of the medical encounter
2) 5 min to cover the closure of the medical encounter
3) 10 min of discussion

**Conclusion (20 min)**

1) Constructive feedback from standardized patient to trainees
2) Constructive feedback from supervisors
3) Debriefing to review the key learning point of the practice sessions

**Program Evaluation (5 min)**

# Appendix A

## Rationale for the Communication Framework

Specific to T21, reviews of the literature on both a national and international level have shown that parents repeatedly remember negative experiences when hearing a diagnosis of Down Syndrome applied to their child.[3,7,14,15] When preparing to deliver the news, healthcare professionals should consider who, where, and when it will be delivered. When initiating a conversation about an unexpected T21 diagnosis, it is critical that the news not be framed as "bad" while still acknowledging that it is life altering. The first words set the tone for the entire conversation with many mothers recalling what with initially said over two decades later[14] so it is vital that this be done thoughtfully and positively.

In regards to who should communicate the diagnosis, parents report a strong preference for the news to be delivered by a single empathetic physician who is knowledgeable about T21.[16] The diagnosis should be made when both parents are present.[16] Mothers told alone endorsed feeling burdened by the responsibility of sharing the news with their partner and reported great dissatisfaction when their partner was informed before them.[16]

Timing of the news has a significant impact on how parents received a postnatal T21 diagnosis. Given the need for early medical intervention in many babies with T21, as well as the fact that classic phenotypic characteristics often raise early concerns, the majority of parents are told within the first 24 hours of life.[7] Within this time frame, the overall mean parental satisfaction regarding timing of the news was 56% with the majority of parents, 77%, satisfied when they were told within 3-5 hours of their baby's birth. Strongly negative experiences have been reported when diagnosis was done at times perceived as both "too soon" and "too late" regardless of the absolute amount of time that was allowed to pass between the delivery of the baby and the breaking of the news.[7] With this in mind, efforts should be made to balance the mother's recovery after birth with timely initiation of delivering the news.

Prior to delivering the diagnosis of T21, ensure that you are aware of the major physical characteristics associated with the syndrome and review the screening guidelines for children with Down syndrome so that you may address any concerns parents have. It may also be useful to remind yourself of the typical forms of prenatal screening used for T21 (ex. IPS, first trimester screen, nuchal translucency) as parents may have questions about why the diagnosis was not detected prenatally. Remember that T21 is a common diagnosis that is most often determined by spontaneous mutations so parents of children with T21 have varying levels of baseline knowledge and personal intellectual functioning. It is important to meet families' current understanding and add to them in a way that is appropriate for their lives.

The setting for the conversation should be private, quiet, and free of unfamiliar personnel to promote an open and safe atmosphere for parents to react without fear of judgment.[3, 16] In particular, visitors and additional healthcare staff should be asked to leave the room. Parents expressed intense dissatisfaction when the news that their child had T21 was shared in front of hospital roommates, extended family, or friends. If a mother is alone, it may be important to amend this at the mother's request so that a single important person is present for the conversation to provide support.[3] Healthcare professionals should also be prepared to provide extended amounts of time to the encounter and work to limit the number of interruptions (ex. pagers) that occur as parents were more likely to remember the experience of receiving the news as negative if they felt rushed or interrupted.[14]

Language used to deliver the diagnosis is of critical importance both in terms of what is said and how it is phrased. The SPIKES format is a well-developed communication guideline developed for "breaking bad news"

to adult oncologic patients and their families.[1] Recognizing that Pediatric patients are not simply "little adults", it has been adapted over time to include a more collaborative approach that facilitates family-centered conversations.[18] While the basic SPIKES tenets remain relevant to preparing for a challenging discussion, certain aspects have been proven antiquated in helping families to reach a true understanding of what healthcare professional want to communicate in critical conversations. In essence, there has been a shift to recognize that, when faced with challenging or unexpected news, even the most knowledgeable individual may struggle to grasp the full implications of what is being communicated.[9] With this in mind, there is growing support for implementation of the "teach back method" into the delivery of life altering news which places the burden on practitioners to use proactive methods to check for comprehension ("Help me to see if I've left anything out").[4, 9] By validating questions as a normal, and even expected part, of a critical conversation, you create an atmosphere that is more conducive to honest dialogue and release families from feeling guilt or embarrassed if they are still not clear about certain details they were told. Essentially, you recognize that communication is not a linear phenomenon as suggested by the SPIKES method but rather a multi-tiered complexity consisting of what is intended, said, heard, and ultimately understood.

For the first conversation, information should be limited to the medical conditions children with T21 are likely to face in their first year of life.[16] The process of receiving an unexpected diagnosis can be overwhelming enough, so information about possible issues later in life should be deferred. Information should be communicated in a practical, confident, accurate, and positive manner. Parents reported feeling resentful of information they perceived as vague, outdated, or overly pessimistic.[16] Terms such as "mongolism" should never be utilized as they are hurtful and inappropriate. The process of hearing the news can be shocking or even traumatic for some families.[7] As you share the news with them, be ready for a variety of reactions including but not limited to: shock, anger, devastation, helplessness, and rejection.[17] It is important to empathize with families regardless of their reactions and demonstrate your own honest display of emotion as appropriate as parents felt comforted by this rather than deterred.[3]

# Appendix B

## Clinical Scenario and Goals of Encounter

| | |
|---|---|
| **Reason for consultation** | You have been called by an Obstetrician from the Labour and Delivery Ward. The Obstetrician states that he has just delivered a baby girl in Room 15 to a healthy 28 year old G2T1P0A1L1 mother named Amy. The baby girl was born 3-4 hours ago and the L&D team has concerns. The RN has commented that the baby appears a "little floppy" and that she has had difficulty latching. The OB staff has voiced to you that he suspects the baby may have Down syndrome given some of her facial features but he is not sure. No one has raised their suspicions to the parents. You are consulted to assess the baby for a diagnosis of query Down syndrome and deliver the news to the family if it is correct.<br><br>As you enter the room, you see Amy holding her baby. She is surrounded by multiple people who introduce themselves as friends who are just on their way out. Amy's partner is not in the room as he has left to bring their parents home. She seems curious as to why you're here. |
| **Trainee's Goals Reminder** | 1. *Setting:*<br>• Establish a safe and secure environment in which parents feel free to express themselves<br>• Work to ensure that parents to receive the news together with distractions and non-essential personnel minimized throughout the discussion<br>2. *Perception:*<br>• Clarify if parents have recognized any features that they are concerned about<br>• Clearly explain your role as well as the reason you have been asked to see them<br>3. *Invitation:*<br>• Offer parents the opportunity to share their main questions and concerns<br>• Clarify their baseline understanding of T21 so that you may appropriately build on it<br>4. *Knowledge:*<br>• Describe T21 in practical terms that highlights what features make you suspicious of the diagnosis for their child as well as what is "typical" about the child<br>• Clarify immediate medical concerns and outline corresponding management<br>5. *Explore and Empathize:*<br>• Normalize parental feelings and validate their reactions in a way that shows you appreciate their experience even if you do not feel the emotion yourself<br>• Adjust the rate of information delivery to the needs of the family<br>6. *Strategize and Summarize:*<br>• Ensure parents have an understanding for the immediate steps that will be taken to care for their child and empower them to get actively involved in their child's care<br>• Provide parents with time to reflect on the news and schedule follow-up meetings with as appropriate |

# Appendix C

## Key Components for the Communication of a T21 Diagnosis

**Note: this is a guideline of steps to facilitate communication. They do not necessarily need to be performed in the order provided. Many steps may occur or re-occur throughout the whole encounter.*

| Suggested Communication Strategies | Rationale |
|---|---|
| * *Greet the parents and introduce yourself*<br><br>* *Inquire about father's/partner's presence or absence* (if applicable) | Clarify your role to establish trustful relationship.<br><br>Work to inform parents together as this promoted a greater satisfaction with the overall process. |
| * *Choose a setting that is quiet to minimize disruptions* (remember to turn your phone and/or pager to vibrate)<br><br>* *Encourage unknown or additional people to leave the room* (i.e. RN, acquaintances) | Promotes safe and therapeutic space for what may be a challenging or sensitive conversation.<br><br>Allows parents to freely express themselves without feeling rushed, interrupted, or judged by others. |
| * *Be sure that the parent(s) have seen their baby and that s/he is in the room with you*<br><br>* *Refer to the baby by his/her name and look at him/her as appropriate* | Destigmatize the diagnosis as early as possible to promote attachment.<br><br>Parents should see you role modelling natural interactions with them as well as with the baby. |
| * *Sit down so that you are on the same level as the parents throughout the discussion*<br><br>* *Make eye-contact with the parents and maintain a calm but confident demeanor* | Reinforces that you are equals and minimize feelings of paternalistic communication.<br><br>Promotes a therapeutic alliance and decreases the anxiety that can be bred by uncertainty. |
| * *After congratulating parents on the birth of their baby, if you have not already done so, you should deliver a "warning sign"*<br>1. "I've been asked to see you because the OB team has some concerns about your baby's [ex. overall lower muscular tone]…"<br>2. "While examining [name of baby/your baby], I noticed some features that make me think of Down syndrome [ex. flat nasal bridge, upslanting eyes]…"<br><br>* *Clarify whether parents have noticed anything "unusual" or "unexpected" about their baby and, if so, what they observed* | Recognizing that the delicate nature of this conversation may trigger a variety of emotions, parents should begin by receiving congratulations on the birth of their baby as this prepares them to receive unexpected new in an optimistic manner.<br><br>Mothers frequently report noticing something "different" about their baby even before the diagnosis of T21 is given. Clarify for identified features whether they are typical to T21 or unrelated. |
| * *Clarify how parents understand T21 so that you may build off their existing knowledge base (pay attention to their language)*<br>1. "What have you heard about Down syndrome?"<br>2. "Have you ever had any personal experience with someone who has Down syndrome?"<br><br>* *Pay attention to the language they use so that you may match the complexity of your explanations to their own understanding* | T21 is a relatively common diagnosis so it is important to appreciate parents' baseline knowledge.<br><br>Studies have shown that only ½ of parents felt information conveyed was easy to understand. |

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| | ** Ask parents what they would like to hear about first and address this issue if they have a preference so that you may focus on answering their concerns and questions*<br><br>*1. "Is there anything you would like to discuss?"*<br>*2. "What are your questions?"*<br>*3. "Is there anything you would like to understand better"* | Allows parents to guide and lead present encounter so that you may address their chief concerns early on.<br><br>Assume that what parents raise is the most important for them to know at first. Other concerns that are less important for them will come later. |
| *Communication strategies to use during the entire encounter* | ** Be honest but sensitive when disclosing that you suspect their child may have T21 and provide specific rationales as to why*<br><br>Ex. "Some of the physical features [insert specific features] we see in your baby are commonly seen in babies affected by Down syndrome or Trisomy 21"<br>** Define T21 using simple and practical terms*<br><br>Ex. "Down Syndrome is a genetic condition that occurs when someone is born with an extra chromosome" | Mothers report remembering what was initially said over twenty years later. Language should be thoughtful and clear.<br><br>Be mindful that technical jargon can trigger miscommunication even if inadvertent.<br><br>Initial explanations should be succinct and easy to assimilate as parents are likely to feel a certain degree of shock that when hearing the news. |
| | ** Use a slower pace while delivering the news and observe verbal as well as non-verbal cues*<br><br>**Identify cues using general "gentle" descriptions*<br><br>1. "I recognize this may be unexpected..."<br>2. "I can understand if this comes as a shock..."<br>3. "I appreciate that this news may be startling..."<br><br>** <u>Avoid</u> offering personal experiences and opinions that are not solicited as these <u>may not</u> reflect how parents actually feel* | Parents describe their first reactions to their child's T21 diagnosis as: shocked, angry, devastated, overwhelmed, stunned, and/or helpless.<br><br>It is crucial to validate and normalize the initial reactions, which will impact how well the next steps of the encounter will evolve.<br><br>Be very sensitive to how a child with developmental delay may fit into the varying cultural, racial, social, and religious backgrounds of individual families. |
| | ** Acknowledge parents' emotions and help them to process their own reactions to the news*<br><br>*EXPLORE*: "How does that make you feel?"<br>*VALIDATE*: "It's natural to feel overwhelmed."<br>*EMPATHIZE*: "I can see that this is difficult for you... I'm here to help however I can."<br><br>** This is <u>not a single step</u> and should be performed as appropriate throughout the conversation* | Uses active listening techniques to reinforce the therapeutic alliance and demonstrate you care.<br><br>Avoid language that apologizes for the diagnosis or implies what parents are feeling (ex. I know this might seem like a devastating loss...). This can seem overly negative and may not reflect how parents truly feel. |
| | ** Allow for silence and time without exuding a sense of unease*<br><br>** If you feel the dialogue has broken down or that parents are too overwhelmed to continue, offer to return later* | Only ½ of parents report that they felt the physician informing them of their child's T21 diagnosis gave them enough time to absorb the news. |

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** After addressing parents questions or concerns, key knowledge points should be communicated to parents as they arise in conversation including:*

- Individual differences in intellectual functioning and that this cannot be predicted at birth
- Specific positive attributes such as warm and caring personalities with an openness to displaying affection
- Medical issues in first year of life (ex. congenital heart defects, gastrointestinal atresia, transient myeloproliferative disorders)
- Breakdown of screening their child will receive early on and a rationale for why it will be done

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Degree of cognitive impairment can vary from mild (IQ 50-70), to moderate (IQ 35-50), or occasionally severe (IQ 20-35) and will reveal itself over time.

Identify major medical problems their child may face and remove uncertainty by specifying what measures will be taken to treat or screen for these issues.

Parents report resentment when information was seen as outdated, inaccurate, overly negative, or vague.

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** Defer conversations about conditions that may affect children with T21 later in life, unless they specifically ask for.*

Ex. AML, ALL, celiac disease, seizures, obesity, Alzheimer, and depression

** If parents inquire or if you feel appropriate, highlight how children with T21 can live productively and well within today's society*

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Children with T21 require lifelong screening so there is time for these issues to be addressed at a later date as parents report this can be overwhelming in the first conversation.

This should be driven by parent interest but well known positive experiences such as involvement in the Special Olympics, work positions, and community roles may be discussed.

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** Re-evaluate parents' understanding to see if salient points have been communicated successfully*

Ex. "We've covered a lot today. I want to make sure things were explained clearly. Please help me see if I left anything out"

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By resetting expectations to frame questions as normal, you minimize feelings of embarrassment or inadequacy so that you can effectively provide a clear and robust explanation to their concerns.

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** Reiterate the specific steps in medical management will be taken in the next few days*

** Match the level of detail you provide about upcoming investigations and treatments to the readiness of the parents*

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Remove uncertainty and clarify what will be done for their baby. Should encourage early involvement in child's care and belief that all necessary steps will be taken on their child's behalf.

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** Provide parents with information regarding local support groups and community initiatives*

** Supply parents with a handout containing information related to T21 and, if not available, provide a list of up-to-date electronic or print resources*

** Support parents by saying that they are not alone and you can come back for further clarifications or answering questions as needed*

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Families should feel well-connected to healthcare supports as well as other families so they feel well taken care of and know they are not alone.

Parents report feeling more optimistic when given current print materials so that they may research additional information at their own pace.

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** Conclude the conversation on a positive note*

** Plan a follow-up with them within the next 24 hours*

** Encourage parents to keep track of any questions that arise and reassure them that you will address them when you return*

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Parents should be left with a sense of hope and an understanding that they are not alone.

By coordinating follow-up, you provide time for them to process the information provided and give a direct demonstration of the ongoing support they will receive throughout their child's life.

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# Appendix D

## Knowledge Based Principles - What Parents Want to Know [2, 8, 17]

- **What is it and why did it happen to my baby?**
  - Genetic condition caused by presence of all or part of a third copy of chromosome 21 (also known as T21).
  - Approximately 95% of cases are due to spontaneous mutations (non-disjunction).
  - Generally, the recurrence risk is approximately 1% although this has some variability based on maternal age-related risk (i.e. higher risk of recurrence with increased maternal age).
  - About 3-4% of cases are due to chromosomal translocations with approximately 1/3 of these (i.e. 1% of all cases of Down syndrome) occurring due to hereditary inheritance patterns.
  - The remaining 1% of cases is due to mosaicism.

- **Why do you think my child has Down syndrome?**
  - Children with T21 are individuals but they share many physical characteristics including: hypotonia; epicanthal folds; flat nasal bridges; upslanting palpebral fissures; speckling of the iris; abnormal auricles; hyperflexibility; excessive skinfolds in the posterior aspect of the neck; a single transverse palmar crease; and a wide gap between the first and second toes.

- **How common is Down syndrome?**
  - Estimates vary but the evidence shows that, overall, approximately 1 out of every 700 babies born is diagnosed with having Down syndrome.
  - Although the incidence increases with maternal age, the majority of children (i.e. approximately 80%) with T21 are born to women under 35 years old as this is in keeping with the baseline higher fertility rates.

- **Could I have prevented this?**
  - There is prenatal screening that can help to diagnose T21 before your child is born but, because most diagnoses are sporadic, there is nothing you could have done to prevent it from happening.

- **What is my baby at risk for right now?**
  - The most common conditions affecting neonates with T21 who are less than 1 month old include:
    - Hypotonia (correlates to feeding difficulties and aspiration risk)
    - Hearing problems (75%)
    - Congenital heart disease (40-50%)
    - Polycythemia (18-64%)
    - Feeding problems (correlates to the degree of hypotonia seen)
    - Cataracts (15%)
    - Gastrointestinal atresias (12%)
    - Gastroesophageal reflux
    - Constipation
    - Transient myeloproliferative disorder (10%)

- **What will be done for my baby in the first few weeks of life?**
  - Key points to mention include: a chromosomal analysis to confirm diagnosis; an echocardiogram to screen for congenital heart defects; a swallowing assessment for aspiration risk; an eye exam for cataracts; newborn hearing screen; history and exam for duodenal and anorectal atresia; baseline CBC for transient myeloproliferative disorders and polycythemia; typical newborn screening with particular emphasis on TSH levels to assess for congenital hypothyroidism; a discussion regarding risks of respiratory infections; and a discussion of recurrence risk.

- **What is the life expectancy of individuals with Down syndrome?**
  - Average life expectancy in Canada is currently into the mid-50 with 10% of adults living to be 70+ years.

# Appendix E

# Resources


1. Baile W, Buckman et al. SPIKES-A Six-Step Protocol for Delivering Bad News: Application to the patient with cancer. *The Oncologist* 2000; 5(4): 302- 311.
2. Bull, M., & the Committee on Genetics. (2011). Clinical Report - Health Supervision for Children with Down Syndrome. *Pediatrics*. 128(2), 393-406.
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