

Child-Centered Care: Strategies to Alleviate Anxiety in Pediatric Oncology Patients and Families during Radiotherapy.



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## Declaration of Conflict of Interest

I have no actual or potential conflict of interest in relation to this presentation

## Background: Safety Concerns from Pediatric Patient & Family Perspective

### *Emotions:*

- *Fear*
- *Anxious*
- *Pain*
- *Helplessness*
- *Loneliness .....*

### *Fear of*

- *Pain from procedure*
- *Death*
- *Disease progression*
- *Big equipment*
- *Separation from parents*
- *Being not understood*
- *Not able to understand*
- & So, on .....



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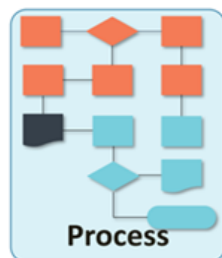
## Aim:

- The objective of this Quality Improvement Project is to establish a comfortable and secure environment for pediatric patients undergoing radiotherapy and their families. Additionally, the project seeks to decrease the frequency of sedation required for pediatric patients during radiotherapy sessions.

To increase the patient satisfaction index of pediatric patients undergoing radiotherapy in NCCCR from 3.6 to 4.5 in 6 months (by Nov. 2023) and further to 4.8 by April 2024.



- Pediatric Patient Satisfaction Index



- Compliance to department orientation to patients and family prior to Radiotherapy
- Compliance in engagement with child life specialists
- Compliance in understanding child specific requirements
- Compliance in providing rewards and gifts



- Percentage of variation in sedation for pediatric patients for Radiotherapy

# Driver Diagram

## Aim/Goal

SMART Aim: To increase the patient satisfaction index of pediatric patients undergoing radiotherapy in NCCCR from 3.8 to 4.5 in 6 months (Nov. 2023) and further to 4.8 by April 2024.

Global Aim: To increase pediatric patient experience and safety

## Primary Drivers

Leadership support

Patient & family orientation & education

Staff engagement

Fulfil child specific requirements

Feedback mechanism

## Secondary Drivers

Leadership engagement

Support in decision making

Creating play area and Procurement of gifts

To provide patient and family education about RT at various levels, from chemo unit, before and during first consultation, before simulation and first day of treatment

Involve patient and family in plan of care

Ensure Person Centered Care

Enhance channels of communication

Create pediatric treatment team

Increase staff knowledge on communicating to child and family

Emphasize empathetic and compassionate patient interactions

Create What Matter to You form for pediatric patients

Introduce RTT Consultation

Introduce WMTY in initial consultation

Implement survey to gather feedback from patients

Analyze survey results to identify areas for improvement and address patient concerns

## Change ideas /Concepts

- Staff recognition program
- Engaging and motivating children ( play area and provide rewards, gifts )

- Develop educational videos specific for pediatric patients
- Develop pretreatment orientation program
- Communication on diagnosis to the child

- Provide training session for Radiation Therapists, Oncologists and Anesthetists on person centered care , effective , empathetic and compassionate communication.
- Collaborate with various teams including child life specialists from Pediatric unit
- Share patient stories

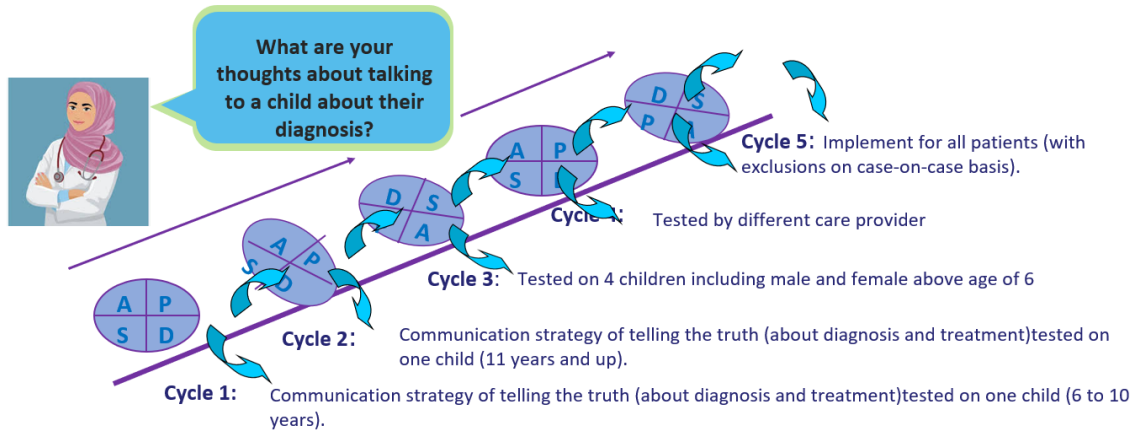
- Provide rewards and gifts to child based on child's hobby, favorite characters
- Understand interests or hobbies of child
- Understand child's fears, worries, sensitivities

- Develop patient survey
- Conduct regular collaborative meetings to discuss the findings
- Foster a culture of continuous improvement within the team

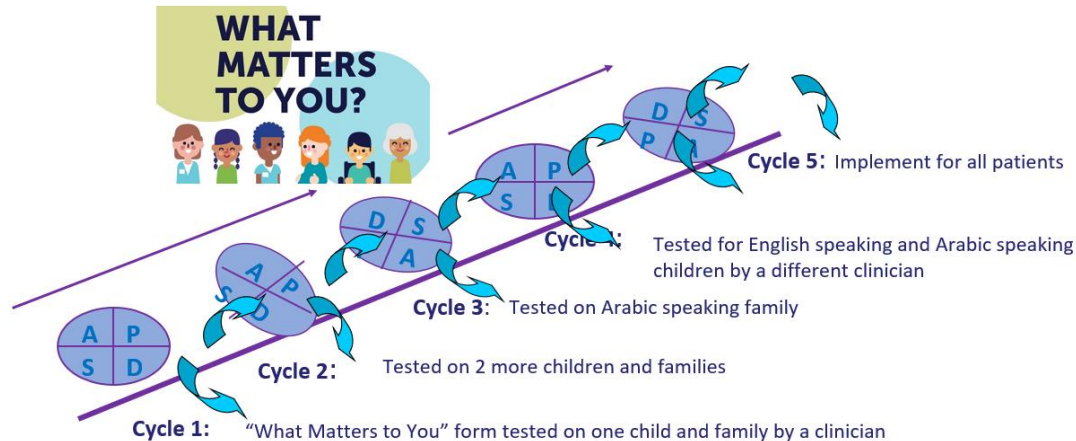


# Interventions & PDSA Cycles:

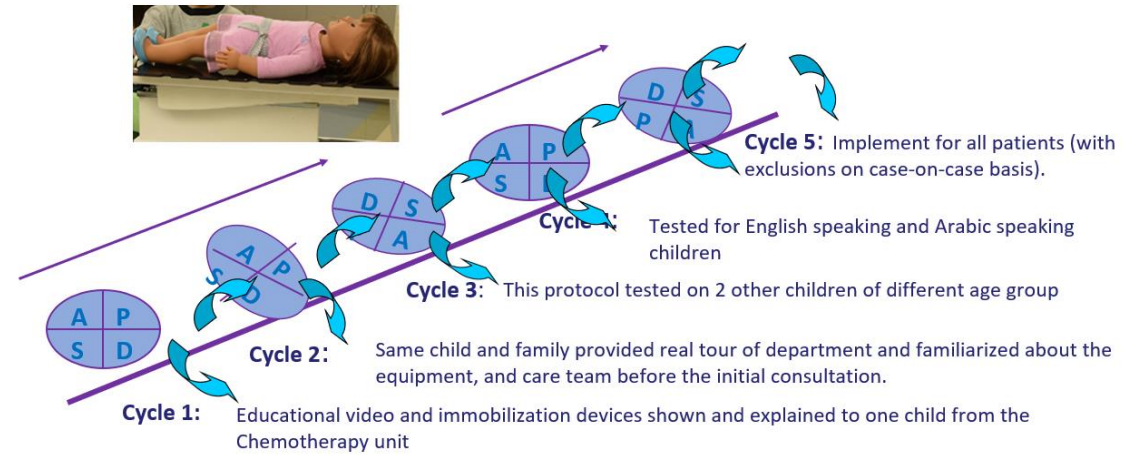
**PDSA Aim:**  
The Importance of Truth-Telling: How to Talk to a Child When They Have Cancer



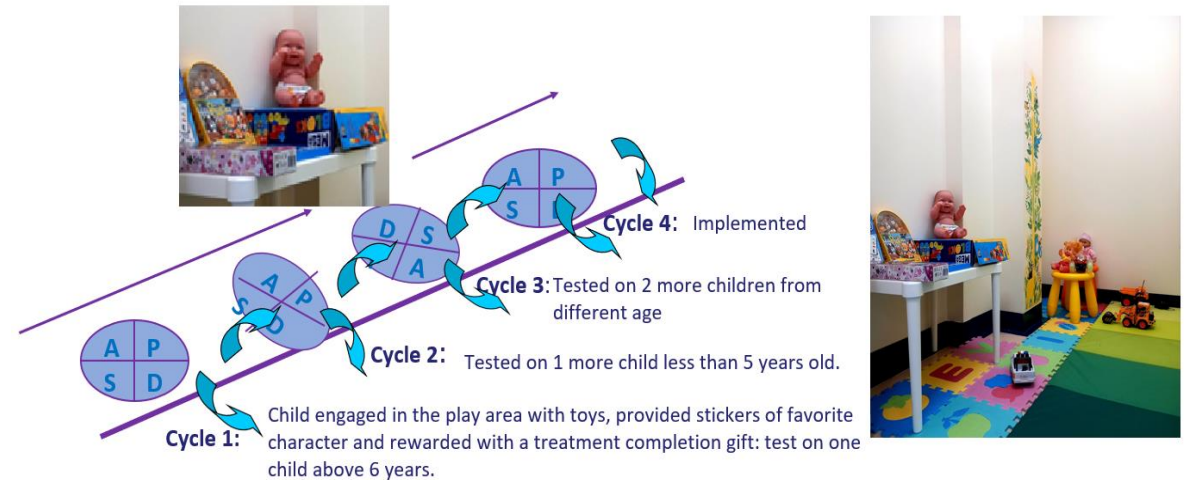
**PDSA Aim:**  
To understand child specific information: Hobbies, favorite characters, fears, worries, sensitivities.



**PDSA Aim:**  
Orientation of child and family to Radiotherapy workflow, procedure and team prior to initial consultation



**PDSA Aim:**  
Engaging and motivating children to gain confidence and provide friendly environment.



## Other interventions:

- Language bank to mitigate language barrier:
  - 21 volunteers, capable of translating 15 languages . Some volunteers can translate multiple languages and as a result we have additional 35 resources in this initiative.
- Patient feedback form with elements of Person Centered Care, including
  - Infrastructure meeting the requirements
  - patient education on health issues, plan of care, treatment options
  - efforts taken to understand and incorporate what matters to the patient
  - efforts taken to overcome language barriers
  - efforts taken to respect and safeguard religious and cultural values and beliefs
- Sustainability: Quality Indicators : on patient education and cultural safety (Started Jan 24)

6. Facilities provided at the department (waiting area, toilets, treatment rooms, prayer room etc) meets your requirements

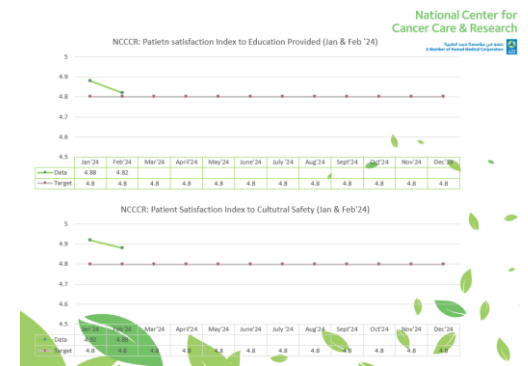
7. How satisfied are you with the efforts made to help you understand your health issues, treatment options, and the treatment process

8. How satisfied are you with the efforts made to understand and incorporate what matters most to you throughout your entire treatment journey?

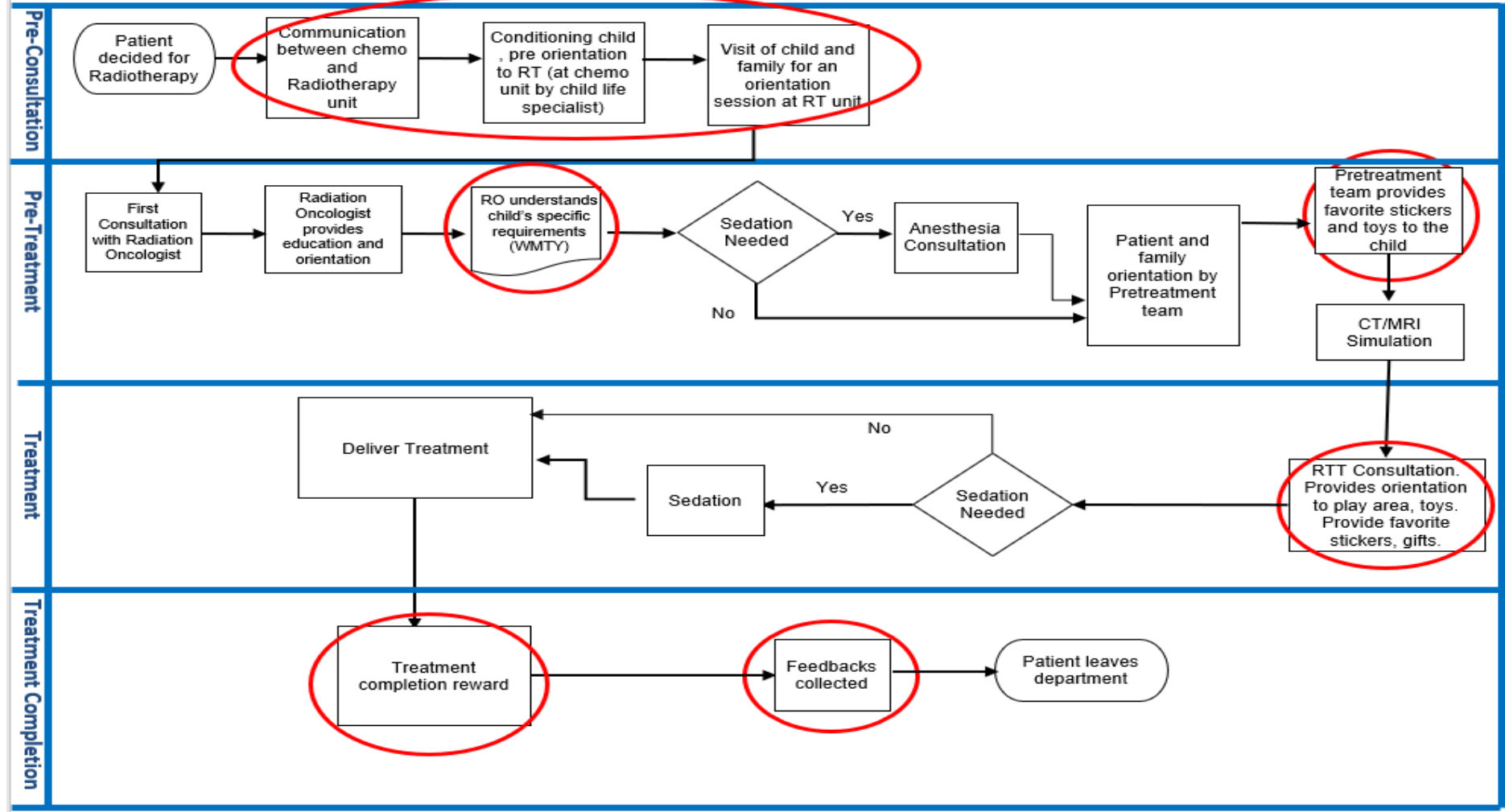
9. How satisfied are you with the efforts made to assist you in overcoming any language barriers, if any?

10. How satisfied are you with the efforts made to respect and safeguard your cultural and religious values and beliefs?

2024 New measures				
#	KPI Name	Definition	HSPA, NCCCR, Corporate	Data collected(1) Validation Done(2) To be presented (3) Implemented (4)
	Patient satisfaction index to patient education on Radiotherapy	The Patient Satisfaction index to patient education is a metric that represents the satisfaction levels of patients with the patient education provided. It is measured using Patient Satisfaction Surveys enabling patients to rate how happy they were with the patient education provided on a 1-5 rating scale.	NCCCR	4
	Patient satisfaction index to cultural safety at Radiotherapy department	The Patient Satisfaction index to cultural safety is a metric that represents the satisfaction levels of patients with the efforts in safeguarding cultural and religious values and beliefs. It is measured using Patient Satisfaction Surveys enabling patients to rate how happy they were with the cultural safety aspects provided on a 1-5 rating scale.	NCCCR	4

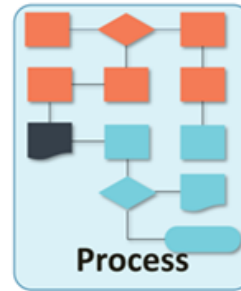
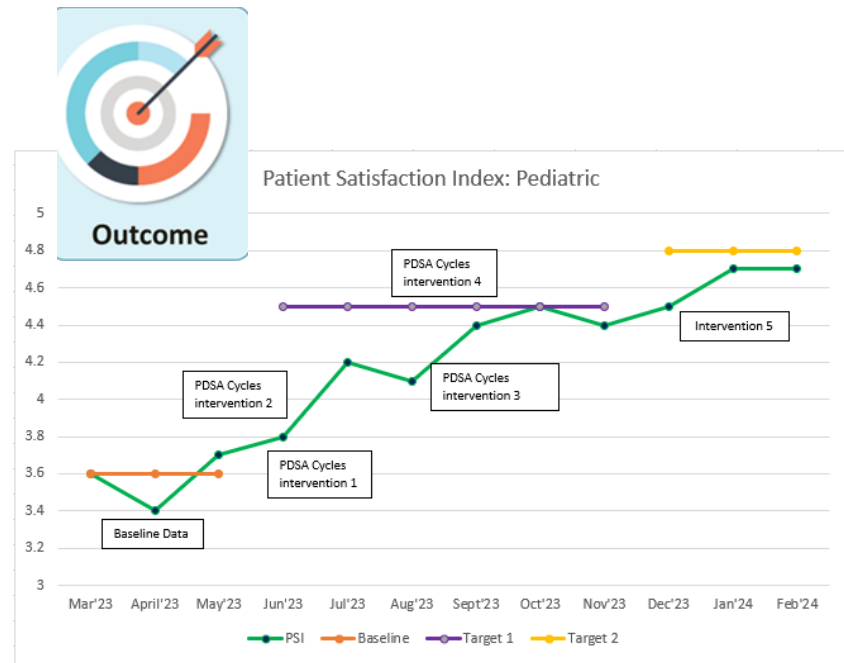


# Advanced Process Map

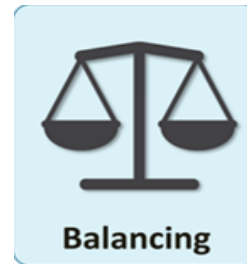




# Results:



- Compliance in engagement with child life specialists : 100%
- Compliance to department orientation to patients and family prior to Radiotherapy: 78%
- Compliance in understanding child specific requirements: 90%
- Compliance in providing rewards and gifts : 85 %



- Percentage of variation in sedation for pediatric patients for Radiotherapy : 22% Reduction in requirement of sedation for total session

## Conclusion:

- Highly relevant in Indian context. India has one of the highest incidence of paediatric cancers, globally. 50,000 new pediatric cancers annually diagnosed in India comprise about 20% of all pediatric cancers in the world (International Incidence of Childhood Cancer).
- Pediatric patients and family requires immense support for cultural and emotional safety, beyond physical safety. This is an opportunity for improvement in safety programs.
- The role of Child Life Specialists is highly significant in educating, preparing and supporting children and families through difficult tests and procedures related to chronic or acute illness. The need for engaging child life specialists in our Pediatric settings especially Oncology is need of an hour.
- Transition towards Person Centered Care (PCC): Initiatives aiming at engaging pediatric patients and family have shown a significant role in enhancing patient experience and reduction in instances requiring sedation.
- Including elements of PCC in patient feedback forms and measurable elements reflecting cultural, emotional and psychological safety helps in continual improvement and sustainability.



This project is a collaborative work between the Radiation Oncology team & Anaesthesiologists @ Hamad Medical Corporation and Child Life Specialists, SIDRA Hospital.

Thank You



# Common Reasons For Not Talking to a Child About Their Diagnosis

Child is too young to understand

They will be scared, sad or not be able to cope

The child will refuse to comply with procedures and/or treatment.

Religious/cultural beliefs

Caregivers feel uncomfortable or unsure what to say

Caregivers want to wait until they feel better/end of treatment

Courtesy : Child Life Specialists, SIDRA Hospital



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## Disadvantages of Not Talking to Children :

- Children of all ages, including toddlers, often sense changes in caregivers' behavior and mood, in addition to overhearing conversations. They will know something is going on, even if they don't/can't say anything.
- Children may make-up stories about why they're in the hospital/sick, which may be far worse than what the reality is.
- Some children may believe they are sick because of something they said or did
- It can cause a loss of trust by the child (with/toward parents and medical team)
- The child may find out the truth from someone/somewhere else
- It can affect coping and compliance
- It can cause fear in other children about their bodies/health through incorrect information being passed along, i.e.:
  - Child with cancer: I go to the hospital to take vitamins.
  - Friend of that child: I take vitamins too, does that mean I will lose my hair?

*Courtesy : Child Life Specialists, SIDRA Hospital*



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## Research Shows...

Children do understand and they may do better with more information.

'Research has proven that truth telling benefits coping, emotional regulation and an improved understanding of diagnosis' (Smith, L. *et al.* 2019).



When talking to a child the following should be considered:

- Actual Age
- Developmental Age
- Learning style/preference
- What they already know
- Who will be present when speaking with the child
- Assure enough time and privacy to talk without interruptions

Courtesy : Child Life Specialists, SIDRA Hospital



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## Preschoolers (3-5 years old)

- Do understand what is happening
- Do not need a lot of information, especially all at once
- Have short attention spans; may only be able to listen/focus for a short time
- Use simple but truthful words
- Include words they may regularly hear throughout treatment (chemo, port).
- Understand best through sensory information: what they see, feel, smell, hear, taste
- They learn best through play, hands-on activity, rather than just being told
- May want to use a doll/stuffed animal and/or pictures to help with talking to preschoolers
- Re-assure them, they did not say/do anything that caused them to be sick

*Courtesy : Child Life Specialists, SIDRA Hospital*



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## School age (6-10 years old)

- May use a variety of methods depending where child is developmentally
- Prepare what you want to say/explain to the child
- Don't need to use the word cancer, but can use the type (leukemia, lymphoma) with further explanation
- Reassure the child they did not do or say anything that caused them to be sick
- May want to include visuals, stuffed animal/dolls, for teaching
- May be able to tie in what they have learned in school with their diagnosis

*Courtesy : Child Life Specialists, SIDRA Hospital*

## Teens (11 and above)

- Teens do better when working in partnership with caregivers and having choices about their care. This gives them control of their diagnosis.
- Teens often think about their disease in terms of how it will impact their daily life: school, friends, appearance, activities.
- Reassure the teen they did not do or say anything that caused them to be sick.
- Be honest and factual with information.
- Teens may be more aware of what is going on. They may have gone onto Internet to look for information - may be correct or incorrect
- Teens tend to want more information than younger children.
- Give time to process information and allow for questions to be asked.
- They may ask more detailed questions than younger children.

*Courtesy : Child Life Specialists, SIDRA Hospital*

## Tips for Children of All Ages

- It's okay to answer, "I don't know," to a child's questions. Try to find out the answer.
- It's okay for children to show their emotions. This will encourage them to be open with, as well as validate, their feelings.
- Avoid making promises you can't keep; will break trust; cause issues for future appointments.  
Examples:
  - "I promise no needles."
  - "I promise we will go home today." (especially if you know you may need to be admitted)
  - "It won't hurt."
  - "Finished." (halfway through a procedure)

*Courtesy : Child Life Specialists, SIDRA Hospital*