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## Clinical Pearls of Pediatric Brain Tumors for the Advanced Practice Nurse

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### Disclosures

Lauren Hancock and Kelly Ridgway have no conflicts of interest or industry relationship to disclose.

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### Learning Objectives

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## Learning Objectives

- The learner will be able to implement 3 improvements to clinical practice when caring for patients with brain tumors.
- The learner will be able to summarize standard therapy for common pediatric brain tumors.

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## Introduction

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## Introduction

- Thank you for attending - especially virtually! We wish we were together in person and able to have a more robust discussion and give you more of a chance to share your pearls as well
- We know there may be a wide variety of experience in neuro-oncology in the audience, but we hope that everyone gets at least one new thing from this presentation.
- We are presenting a series of case studies- each case study could be expanded into a full hour of lecture, but we are trying to fit a lot of information into a short time in a "rapid-fire" style. Each case is meant to give you a clinical pearl or practical tip - not to be completely comprehensive.

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## Brain Tumor Overview

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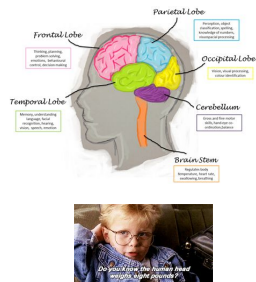
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### Brain Basics

- Development
  - Quarter size of adult brain at birth
  - Full size by 5 years old
  - Myelination almost fully developed by 7-8 years old
  - Frontal lobe is not fully developed until mid-20s
- Weighs approx. 3lbs
- Receives 15-20% of cardiac output



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### Epidemiology

- Incidence of 5.74 cases for 100,000 in children ages 0 to 14 years.
- Estimated 3,540 new cases of childhood primary malignant and non-malignant brain and other CNS tumors are expected to be diagnosed in the United States in 2020.
- Most common childhood cancer in ages 0 to 1 years and 5 to 14 years
  - Leukemia is most common in ages 1 to 4 years



Source:  
<https://cbtrus.org/>

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## Survival

- Five year survival for all primary malignant brain tumors in children ages 0 to 19 is 75.5%
  - Five year survival for all childhood cancers is 84%
  - Varies significantly based on diagnosis
- **Most common cause of cancer-related death in children ages 0 to 14**
  - Previously leukemia



Sources:  
<https://cbtrus.org/>  
<http://www.cancer.org>

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## Pediatric Neurological Exam

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## Pediatric Neurological Exam

- Observation is key - across the room assessment
  - Know the patient's baseline - what is different/new?
- Symmetry
  - Head to toe, right to left, movement/strength/tone, senses, pupils
- Quality
  - Consciousness, activity level, cognition, voice, movement/strength/tone, senses, VS
- Use a toy (their toy is even better) or object for them to focus on
- Listen to family members' assessments and concerns
- Trust your gut and advocate if you think something is wrong
- Describe what you see
  - It is OK not to use the medical terminology if you can't find the right word!



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## Case Study #1 - Low Grade Glioma

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### Olivia

Olivia is a 13 year old young girl with a low grade glioma. She has received multiple previous chemotherapy regimens. She received carboplatin and vincristine as a young child, and subsequently received 18 months of weekly vinblastine. Her tumor has recently shown progression again, and she was started on an oral MEK inhibitor. Since starting on this medication, she has developed an acneiform rash to her face, scattered patches of dry skin, and an ingrown toenail. She is in clinic today and wants to discuss management of her cutaneous medication side effects.

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### General Skin Care Guidelines



- Sun protection
  - Avoid sun exposure, wear sun protection (long sleeves, hats, etc)
  - Use a broad spectrum (UVA + UVB) sunscreen (SPF 50 or higher) and reapply frequently
- Regular face washing
  - With a gentle cleanser such as Cetaphil
- Daily moisturization
  - Moisturize skin with a thick, fragrance-free lotion (such as Eucerin, Aveeno, Cetaphil, or Aquaphor) twice a day after bathing (avoid very hot showers/baths)
- Avoid skin drying products
  - Such as certain soaps or any alcohol-based products.
- Self-monitoring for skin cancers
  - Especially on BRAF V600E inhibitors
  - Regular dermatology follow-up

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## Skin Care - Rash



- Acneiform Rash (Face and Body)
  - Clindagel 1% topical applied after washing face twice daily
  - Doxycycline oral daily or BID (take with food to avoid GI upset)
- Eczematous Rash (Body)
  - Triamcinolone 0.1% ointment to affected areas
  - Bleach baths ([https://nationaleczema.org/wp-content/uploads/2017/06/FactSheet\\_BleachBath\\_FINAL.pdf?59892](https://nationaleczema.org/wp-content/uploads/2017/06/FactSheet_BleachBath_FINAL.pdf?59892))
    - Add ½ cup bleach to a full bathtub (40 gallons) and soak for 10 minutes twice a week. Do not submerge head.
- Scalp Rash/Irritation
  - Daily use of a moisturizing shampoo (such as Dove) or anti-dandruff shampoo
  - Ketoconazole 2% shampoo daily

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## Skin Care - Paronychia

- Monitor toes closely for development of redness/edema
- Soak foot in warm water (+/- epsom salts) for 20 mins 3-5 times daily
- Apply triamcinolone 0.1% ointment daily and mupirocin 2% ointment daily (one in the morning and one at night)
  - Can be used as a preventative measure
- May require oral antibiotics
  - Such as cephalexin
- May require podiatry referral for extraction of nail



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## ACNS1831

- Over the last decade, MEK inhibitors have moved from Phase 1 trials to incorporation into a large Phase 3 trial

CHILDREN'S ONCOLOGY GROUP

ACNS1831



A Phase 3 Randomized Study of Selumetinib (IND # 77782) versus Carboplatin/Vincristine in Newly Diagnosed or Previously Untreated Neurofibromatosis Type 1 (NF1) Associated Low-Grade Glioma (LGG)

A COG Groupwide Phase 3 Study – Open to Institutions within the United States and Canada

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## Case Study #2 - High Grade Glioma

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### Anthony

Anthony is a 10 year old boy with a high grade glioma of the temporal lobe. He has undergone radiation therapy with concurrent temozolomide. He is now on CCNU and temozolomide. Anthony is in the ER after a new onset seizure.

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### Seizure First Aid



- Stay Calm, Maintain Safety and Monitor Cardio-Respiratory Status, Call for Help, Timing is Key
- Medications
  - **lorazepam** (Ativan) 0.05-0.1 mg/kg IV push; may repeat in 10 minutes if no response
    - If no IV access, can administer IM or SL with oral concentrate liquid (2mg/ml)
  - **diazepam** 0.15 to 0.2mg/kg/dose IV; may repeat in 5 minutes if no response
    - May administer rectally - IV formulation at 0.5mg/kg/dose, then repeat at 0.25mg/kg
    - DiaSTAT rectal gel
      - Ages 2-5 years: 0.5mg/kg; Ages 6-11 years: 0.3mg/kg; Over 12 years: 0.2mg/kg
    - Intranasal administration
      - Using a mucosal atomization device
    - IM administration not recommended (can use midazolam if need to use IM route)

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## levetiracetam (Keppra)



- Often first line for seizure prophylaxis
  - Can administer loading dose of 20mg/kg IV x1 for immediate seizure treatment
- Generally well tolerated; do not need to monitor drug levels
- Pediatric patients more likely to exhibit behavior abnormalities than adults (Keppra irritability)
- Starting dose for seizure prophylaxis 10 mg/kg/dose PO BID
  - Can increase dosage every 2 weeks by 10 mg/kg/dose BID
  - Increase up to recommended dose of 30 mg/kg/dose BID (max daily dose 3,000 mg/day)
- Available IV, oral liquid, and tablet
- Can be taken with or without food

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## Monitoring of Anti-Seizure Medications

- Benzodiazepines - more often used as rescue medications
  - lorazepam, diazepam, midazolam, clonazepam
  - clobazam (Onfi): long acting benzodiazepine that can be used daily control
    - Be careful of cloNAZepam vs cloBAZam if both medications are being used
  - Monitor for level of sedation, respiratory depression
- oxcarbazepine (Trileptal)
  - Monitor sodium closely with initiation of therapy (esp first 3 months) for hyponatremia
  - Monitor thyroid function regularly
- lamotrigine (Lamictal)
  - Monitor for development of rash
  - Monitor CBC and liver/renal function regularly

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## Monitoring of Anti-Seizure Medications

- topiramate (Topomax)
  - Monitor electrolytes, including bicarbonate for development of acidosis
  - Monitor heat intolerance (decreased sweating)
- valproic acid (Depakote)
  - Frequent monitoring of liver function, CBC Vitamin D levels
  - Monitor drug levels for appropriate therapeutic (and non-toxic) level
  - Liquid (Depakene) can be less reliable in terms of levels; can cause stomach upset
  - Also available as sprinkles
- phenytoin (Dilantin)
  - Monitor CBC and liver function
  - Monitor drug levels (serum trough concentrations)
  - When administering IV, should have continuous cardiac monitoring
- phenobarbital
  - With prolonged therapy, monitor liver enzymes, CBC, and Vitamin D levels

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## Case Study #3 - Germ Cell Tumor

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### Kyle

Kyle is a 15 year old young man with a germ cell tumor. He has experienced symptoms of diabetes insipidus and receives daily DDAVP. He is receiving chemotherapy as per ACNS1123 and is being admitted for ifosfamide and etoposide with associated hydration. How will you manage his fluid balance while admitted?

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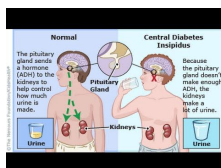
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### Diabetes Insipidus

- Treat with administration of desmopressin (DDAVP), a synthetic ADH
  - Can be nasal spray, oral tablets, or IV
- Increased dose decreases urination and consequently decreases sodium level
- Young children may not be able to compensate appropriately and are more likely to develop hyponatremia with treatment
- May also have concurrent SIADH



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## Fluid Management with Chemotherapy

- Baseline assessment prior to chemotherapy with hyperhydration (cisplatin/ifosfamide)
  - Baseline desmopressin (DDAVP) dose
  - Fluid intake and urine output baseline (any recent changes)
- Keep nausea/vomiting as well controlled as possible
- Frequent sodium checks while admitted (q6 hour or more)
  - Wide variation in sodium levels during hyperhydration (Afzal et al)
  - Sodium check with any change in clinical status
- Likely to require frequent (daily) changes in DDAVP dose (Afzal et al)
- May require PICU admission for continuous vasopressin drip and closer monitoring of sodium levels with hyperhydration
- Consider endocrine consult prior to and during admission

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## Case Study #4 - Craniopharyngioma

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## Daniel

Daniel is a 10 year old with a craniopharyngioma who has undergone a surgical resection and is being monitored with serial MRI scans. He has pan-hypopituitarism and is taking hydrocortisone, levothyroxine, DDAVP, and growth hormone. He is in clinic today for routine follow-up and you are conducting his medication reconciliation.

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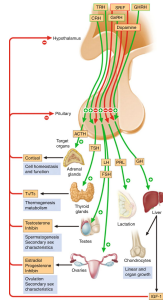
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## Pan-Hypopituitarism

- Endocrinopathies are the **leading secondary cause of death** in patients with craniopharyngioma
- Medication compliance and follow-up are critical for ongoing management




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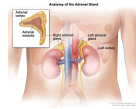
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## Hydrocortisone

- Always measure cortisol level at 8:00am
- ACTH stimulation test
- Daily replacement Oral: 8 to 10 mg/m<sup>2</sup>/day divided every 8 hours; up to 12 mg/m<sup>2</sup>/day in some patients.
  - To replicate cortisol fluctuations that occur naturally throughout the day, the highest doses are typically administered in the morning and midday with the lower dose in the evening
- Stress dose - PO or IM. Dosing is usually 2-3 times the physiologic replacement dose. It should be based on level of physiological stress expected and continued 24-48 hours after resolution of stressor.
  - Stress dosing used for surgical procedures, illnesses, hospitalizations
  - When in doubt, give stress dose




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## DDAVP

- Dosing can be presented in mcg, mg, and mL and depends upon product formulation. Use caution and verify product formulation and dosing units before administering.
- Initial ORAL dose: 0.05 mg twice daily; titrate to desired response
  - Optimal daily dose range: 0.1 to 0.8 mg/day in 2 to 3 divided doses
  - Reported daily dose range: 0.1 to 1.2 mg/day
- Fluid restriction should be observed while finding adequate initial dosage
- Frequent sodium checks recommended
  - At least daily for 1-2 days with each dosage change

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## levothyroxine (Synthroid)



- Regularly monitor TSH and Free T4
- If TSH is low, that doesn't matter as long as Free T4 is normal (being replaced with medication)
- Should be taken in the morning on an empty stomach
- Dosing:
  - 1 to 5 years: 5 to 6 **mcg/kg/dose** once daily
  - 6 to 12 years: 4 to 5 **mcg/kg/dose** once daily
  - >12 years pre/mid-puberty: 2 to 3 **mcg/kg/dose** once daily
  - Adolescents post-puberty: 1.6 **mcg/kg/dose** once daily; adjust dose by 12.5 to 25 mcg/day every 4 to 6 weeks as needed
  - Adjust dose based on lab values (Free T4) and symptoms

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## Growth Hormone

- Growth Hormone (GH) deficiency is one of the most common hormone deficiencies seen in survivors of brain tumors.
  - Important for more than just growth velocity
- Monitor IGF-1 and IGF-BP3 (labs) and bone age (x-ray)
- Growth Hormone Stimulation Test
  - Not always necessary if known cause of deficiency (i.e. brain tumor/radiation)
- GH replacement through daily (or 6 days/week) subcutaneous injections
  - Dosing: SubQ: Initial dose: 0.16 to 0.24 mg/kg **weekly** divided into equal doses 6 or 7 days/week. Dose should be individualized based on patient response; treat with the lowest effective dose.
- Continue GH replacement until growth velocity is <2-2.5cm/year
- Risk of recurrence or tumor growth with GH replacement?

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## Sex Hormone Replacement

- Monitor testosterone/estradiol, FSH, and LH levels
  - AMH (Anti-Mullerian Hormone) in post-pubertal girls
- Dysfunction can present as precocious OR delayed/absent puberty
- Testosterone
  - Administered IM monthly
  - Available as a topical cream
- Estrogen/progesterone
  - Often in the form of oral contraceptive pills (OCPs)
  - Primarily used for amenorrhea
- Dosage determined by individual patient - age, diagnosis, treatment history, response to hormone replacement therapy, and any adverse effects of replacement therapy

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## Case Study #5 - Survivorship

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### Jacob

Jacob is a 17 year old young boy who completed treatment for medulloblastoma 4 years ago. He received surgical resection, craniospinal radiation, and chemotherapy with cisplatin, cyclophosphamide, and vincristine. He is in clinic for follow-up and complaining of fatigue that is impacting his daily life. He does not feel like he has the energy to do things he wants to do, and can barely stay awake through an entire school day.

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### Excessive Daytime Sleepiness (EDS)



- Sleep disturbances are one of the most common complaints of children and AYAs both during and after treatment for cancer
- EDS is defined by the American Academy of Sleep Medicine as “the inability to maintain wakefulness and alertness during the major waking episodes of the day, with sleep occurring unintentionally or at inappropriate times”
  - This must continue almost daily for a period of at least three months
- Try nonpharmacologic management methods, but many times patients with EDS benefit from the use of a stimulant
  - Regular **exercise** is one of the best ways to combat fatigue (Szulc-Lerch, et al)

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## Stimulant Medications



- Methylphenidate (common brand names: Ritalin, Concerta) and Dexmethylphenidate (brand name: Focalin) are commonly used
- Come in both immediate release (IR) and extended release (ER) forms
- Dosages:
  - Methylphenidate:
    - IR: (Methylin, Ritalin) 2.5-5mg BID, titrating up as needed. Some children require TID dosing. Max dose of 60mg/day
    - ER: (Concerta) start 18mg daily and titrate up by 18mg weekly. Mag dose is recommended at 54mg/day, however with monitoring some patients can tolerate up to 104mg/day
  - Dexmethylphenidate:
    - IR: 2.5mg BID at least 4 hours apart. Titrate up by 2.5mg/dose at weekly intervals. Common max dose: 20mg/day
    - ER: 5mg daily. Titrate up by 5mg at weekly intervals. Max dosage usually 30mg/day

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## modafinil (Provigil)

ACCL0922: A Phase II Placebo-Controlled Trial of Modafinil to Improve Neurocognitive Deficits in Children Treated for a Primary Brain Tumor

- Modafinil is a dopaminergic central nervous system stimulant that can be used as an alternative to methylphenidate.
- Studies in adults have shown improved cognition, mood, and fatigue as well as some improvement in processing speed. (Castellino et al)
- More research is needed, although adult and pediatric studies have had limited accrual. (Castellino et al)
  - COG study ACCL0922: Opened 2012, closed in 2016
- *Modafinil is not FDA-approved for use in pediatrics for any indication. Serious skin reactions and psychiatric events have been observed in pediatric patients treated with modafinil. The serious nature of these adverse effects resulted in the FDA's Pediatric Advisory Committee unanimously recommending that a specific warning against the use of modafinil in children be added to the manufacturer's labeling.*

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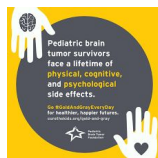
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## Ongoing Impact of a Brain tumor

- Physical
  - Weakness, paralysis
  - Vision loss
  - Endocrinopathies
  - Ataxia
  - Dysarthria
- Cognitive
  - Impaired working memory
- Social/emotional
  - Isolation (patient and family)
  - Parental loss of the child they had before diagnosis
- Financial burden
- Long Term Effects
  - High morbidity - Even long term survivors have many ongoing long-term healthcare needs



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## Case Study #6 - DIPG

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### Emily

Emily is a 4 year old young girl who presented with "one eye turning in" and was referred by her ophthalmologist for imaging. She was found to have a diffuse intrinsic pontine glioma (DIPG). She is undergoing radiation therapy and her family is in clinic to discuss enrollment on an early phase clinical trial. Her parents want to know what it means to be on a Phase 1 study, and how likely this new treatment is to cure Emily.

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### Phase 1 Trials

- To determine the safety of a medication or treatment
- Important for families to know that this treatment is unlikely to be curative, and to discuss all possible options (including not pursuing further therapy)
- When caring for patients on Phase 1 trials, attention to detail is important
  - Many required observations in order to maintain patient safety
- Need to balance quality of life with treatment, and travel that may be required for treatment
- Although research is limited, overall parents do not regret their child's Phase 1 trial participation (Crane, et al)

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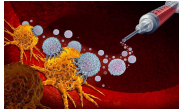
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## New Brain Tumor Therapies

- Targeted/biologic medications
  - Based the molecular make-up of a patient's tumor
  - New combinations of medications
- Immunotherapy
  - PD-1 Inhibitors
  - T-cells/CAR-T Cells
- Medical Devices
  - Tumor Treating Fields



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## Case Study #7 - End of Life

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## Allison

Allison is a 5 year old young girl with a multiply recurrent ependymoma. She just had an MRI scan showing that her tumor has recurred again despite multiple therapies (multiple surgeries, several round of radiation, chemotherapy, and early phase clinical trials). Her family is in clinic to review the MRI scan, and while you are discussing potential treatment options, you let her parents know that we do not have effective curative therapies and you also bring up enrolling in hospice care. Her parents ask, "Isn't that just for when you are about to die? When my aunt went on hospice she had to stop her cancer treatment and we don't want to give up on Allison."

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## Concurrent Care

- Affordable Care Act
  - SEC. 2302. CONCURRENT CARE FOR CHILDREN.
  - A voluntary election to have payment made for hospice care for a child (as defined by the State) shall not constitute a waiver of any rights of the child to be provided with, or to have payment made under this title for, services that are related to the treatment of the child's condition for which a diagnosis of terminal illness has been made.
- **Children may receive curative treatments AND hospice care.**

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## Benefits of integrating palliative care

- Honest discussion of prognosis leads to processing of information and earlier integration of PC into plan of care. (Vargo, 2011)
  - Children may be intuitively aware of their prognosis and want to protect their parents
- Availability of concurrent care
- Symptom management
  - Pain, N/V, Fatigue, Altered mood, Secretions, Agitation, etc.
- Help with decision making

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## Communication

- Open and honest
  - Decreases uncertainty and parental regret
  - Improves hope
- Allow space for silence
- Most parents want to receive information about palliative care (Hendricks-Ferguson, et al. 2017)
  - Evidence shows open communication about prognosis leads to increased trust with providers, increased hope and peace (Mack et al. 2018)

Table 1. Palliative care communication tools

Defining Tool Uses	Valid Responses to End-of-Life	Non-Verbal Response to Emotion
"SHERI" [11] Asking: Prepare the setting for the conversation and introduce discussion (Openness: Assess development to preparation of the clinical information (Structure: Ask permission to discuss new information Knowledge: Provide the main message Support: Respond empathically to emotion Strategy Summary: Summarize the encounter and what will happen next.	"NURSE" [14,15] Naming the emotion statement: "I hear frustration in your voice" Understanding statement: "I understand this is upsetting to you" Respectful statement: "You are here and that's how I have been to your son's care" Acknowledgment: "You are here and that's how I have been to your son's care" Support statement: "We are here to help you and your family." Explain statement: "Tell me about what you were hoping for your child." Silence: Providing silence in the room can potentially strengthen caregiver connection.	"SALAP" [20] Squaring the patient Open body posture Lean toward the patient Eye contact Aligned body posture

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## Resources

- Vital Talk
  - Communication training for providers
  - <https://www.vitaltalk.org/clinicians/>
- Courageous Parents Network
  - Many videos for families caring for a chronically ill child and making difficult decisions for their child
  - <https://courageousparentsnetwork.org/>

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## Conclusion

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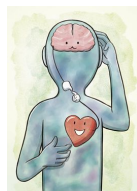
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## When Caring for a Child with a Brain Tumor...

- Be patient
- Listen to the patient and the family
- Know what “normal” is for them
- Every child is unique
- Prognosis can vary dramatically based on diagnosis
- Pay attention to the little things
- Celebrate every milestone
- It's a team effort



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## Caring for Yourself

- Just as important as caring for your patients
- Everyone has a different way to take care of themselves
  - Yoga, meditation, cooking, outdoor activities, time with friends and family, coloring, etc
- Important to process the losses we have at work
  - Add time to a regular meeting to honor the children you have lost
- Wish we could have a discussion and share ways we all care for ourselves
  - COVID-19 and the state of the world makes it even more important to think about yourself and practice self-care
- Join us in a brief Guided Meditation

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## Resources for Families (and you!)

- Pediatric Brain Tumor Foundation
  - <http://www.curethekids.org/>
- The Imaginary Friend Society
  - <https://www.imaginaryfriendsociety.com/>
- Children's Brain Tumor Foundation
  - <http://cbtf.org/>
- Childhood Brain Tumor Foundation
  - <https://childhoodbraintumor.org/>
- Courageous Parents Network
  - <https://courageousparentsnetwork.org/>
- Children's Oncology Group
  - <https://childrensoncologygroup.org/>

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Thank you for attending! Questions?

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