Parenting Through Illness



UCDAVIS HEALTH

COMPREHENSIVE CANCER CENTER

Introduction

Parenting can be hard at baseline and made more difficult when parenting through illness. A caring approach supports coping for the entire family. This booklet is a resource for you, as a parent, navigating how best to include and support your children throughout an illness. It can be used at different points along the journey and is meant to complement your natural expertise as the parent of your child.

Information provided in this resource is original to University of California Davis and represents evidence based best practice. While the strategies covered can be applied to many parenting challenges, this booklet is intended to help you parent as well as possible during a serious illness.

Definitions

Parent: Refers to any guardian of minor children.

Child: This includes children 17 years old and younger (any minor child).

Illness: This term includes all the ways in which your condition effects your personal and family life.

Coping: Strategies used to reduce stress.

Typically developing: This is a general picture of progress for children as compared to peers the same age.

Temperament: A child's consistent style of reacting and coping.



Development & Coping Considerations

Child Development:

Developmental considerations are important when responding to children and creating plans for support during a parent's illness. The following chart outlines typical development. For children with unique needs, seeking guidance from an expert in that area will be helpful.

Child's developmental age: Birth to 2 years (infants and toddlers)				
Typical Development	Concept of Illness	Potential stress reactions		
Learning through senses and play Fear of being away from family	Not able to understand the "what, why and how" of illness	Changes in routine can cause distress or disruption to eating or sleeping patterns Difficulty soothing due to separation anxiety		
How to help				
• Provide physical contact and rea • Keep the child's schedule as co	assuring attention to the child (e.g., nsistent as possible	hug, sitting together, etc.)		
Child's developmental age: 3 to 5 (preschool)				
Typical Development	Concept of Illness	Potential stress reactions		
 Interested in self Physically active Basic language skills Seeks independence Learns through play and questions May confuse what is real and what is pretend (magical thinking) 	May not understand what the illness means but is aware of changes in the household. They feel this as opposed to understanding what is happening Due to magical thinking, they may think that they caused the illness by doing something wrong	May show regressive behavior and loss of recently gained skills. More frequent "meltdowns" or temper tantrums Clingy behavior Nightmares		
How to help				
 Name the illness (e.g., Cancer) Re-enforce that they did not cau and they cannot catch the illnes Provide simple explanations and for new events (e.g., The medic cause my hair to fall out.) 	possible Promote play a your house for feelings and e	 Maintain consistent schedule and keep when possible Promote play and create a "big energy" part of your house for anger or frustration. Talk about feelings and encourage self-expression (art, dance, and music) 		

Child's developmental age: 6 to 11 (kindergarten and elementary school)			
Typical Development	Concept of Illness	Potential stress reactions	
Curious and eager to learn Wants to master tasks	Can understand more about an illness and how the illness may affect a person's body	 Worry and sadness Physical complaints Not as cooperative Issues at school and with friends Withdrawal Testing 	

How to help

- Maintain honest communication throughout illness and include more details for older school-aged children (pictures can be helpful)
- Answer questions and know that repeated questioning is normal
- Provide reassurance about the parent's health
- Talk about feelings and encourage self-expression (art, dance, and music)
- Maintain clear rules and boundaries
- Promote play and create a "big energy" part of your house for anger or frustration
- Find peer support groups for your child

Child's developmental age: 12+ (adolescence)			
Typical Development	Concept of Illness	Potential stress reactions	
More advanced thinking Concerned with self-image Friends matter most	Understands more details about the body and how an illness may affect the body Uses discussion as primary form of learning and processing, and begins thinking about illness, mortality, and the meaning of life	 Worry and sadness Physical complaints Big mood shifts (more sleeping and highly charged behavior) Issues at school and with friends Withdrawal Testing limits Not as cooperative 	
How to help			

• Give complete information about the illness

- Support peer group connection and having
- Talk about feelings and encourage selfexpression (art, dance, and music)
- Encourage physical outlets

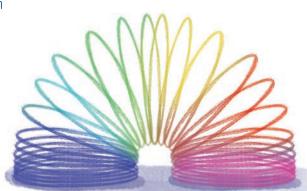
someone to talk to

- Expect that your teen may want to be out with friends even during important times during illness
- Respect your teen's behavior if it doesn't hurt them or others
- Watch for any red flags (abusing drugs or alcohol) and seek help as appropriate
- Find peer support groups for your teen

Childhood Coping:

In thinking about how your child may react to your illness, in addition to development, it's helpful to consider their *coping style* and *temperament*. Here are some questions to think about:

- How does the child react to changes in routine (e.g., a new babysitter is coming over one evening)?
- How does the child do on the first day of school or camp?
- Is the child an attention seeker or someone who prefers less attention?
- How does the child do when problem solving (e.g., quick to find a plan B)?
- Does the child naturally talk about their feelings?



Parents often overestimate the level of stress their child will experience in response to a parent's illness. Children are resilient and tend to cope well when they can continue to engage in their typical routines. Think about your child's temperament and take a moment to answer the questions below:

- If your child knew more about your medical situation, how might they react?
- Are there questions you don't feel equipped to answer or topics that might be harder for you to talk about?
- Are you worried that your child may be so affected by the news that they won't want to engage in their usual routine due to stress and anxiety?
- Do you think that talking about your illness may take it from just a situation in your head to a reality?

Potential coping responses:

Catastrophizer: Imagines worst possible outcomes How this may be expressed... Potential Approaches... Information has been shared with Continue conversations and ensure there are many the child and this has worsened their outlets for working through ideas. coping. They are repeating worst-case • There may be misconceptions and/or other experiences scenarios and are not able to manage that are negatively impacting their coping. their feelings. Consider seeking added outlets for support (e.g., talk) therapy, play therapy). **Sensitizer: Seeks information to better handle stressors** How this may be expressed... **Potential Approaches...** The child is requesting information Regularly schedule family meetings with this child. to help them better understand the Check for understanding throughout to assess how they situation. This sense of mastery over the understand what is being shared. situation is helping the child cope. **Minimizer: Downplays the situation to cope** How this may be expressed... Potential Approaches... The child may take in information as they • Sharing facts and not all the details may be helpful. can manage it. This child will come to Follow the child's lead and continue to create you with questions as they arise so they opportunities for information sharing. can self-dose information intake. **Denier/Avoider: Pushes information away** How this may be expressed... Potential Approaches... To protect themselves, this child will Provide basic information in small doses so this child not want information about the medical can stay informed. situation • Consider seeking added outlets for support (e.g., talk therapy, play therapy).

Through considering how the information above applies to your family situation, family communication can be maximized and you may better be able to anticipate additional support for your child (e.g., preparing coping ideas, work with a counselor, or behavior specialist, etc.).



Communication and Connections

When a parent becomes ill, children need:

- To be included in family communication about their parent's illness
- Outlets for self expression
- Support group opportunities to connect with peers in a similar situation

Family Communication

Ongoing family communication can help children express feelings and get the support they need. When children are not included in family communication about the illness, they can feel emotionally isolated and without supportive outlets for sharing and expressing. Typically, it is best to wait until there is a definite diagnosis before sharing news about an illness with children. However, if an illness is significantly changing a parent's abilities prior to a clear diagnosis, children will need to know that a "work-up" is underway.

Your expertise as a parent and the following considerations will create a thoughtful approach for sharing information with your children.

Timing: Timing is important. First, take time to digest the information yourself. Understanding the medical situation as well as possible will help you answer questions your children may have. It's also important to have this conversation at a time of day when children can afterwards switch to an enjoyable activity to promote ongoing coping.

Environment: Enlist the support of another caring adult when having this conversation. Aim to find a quiet place with minimal distractions. That said, it can be helpful to have a few planned outlets to support coping for children nearby: fidget items and/or drawing supplies (etc.).

Family Communication (continued)

Meeting format: If children have differences in developmental level and/or temperaments, consider having separate conversations with each child. Plan to have shorter meetings, and at any point if you see that a child is no longer engaged, switch gears to play or an expressive activity. Children take care of themselves by taking in hard information on their timeline and they need outlets to support coping.

- Younger children have shorter attention spans and are less able to focus on the future.
- Older children are more future focused and can appreciate more details.
- Children with unique needs will benefit from a plan specifically created for their learning style.

What information to share:

(See "Sample Scripts" in the appendix.)

- Share background information to begin the conversation. Name the illness and emphasize to children that they did not cause it and cannot catch it (if this is correct).
- Find out what the child may already know about the illness.
- Explain the illness in an age-appropriate way. Check for understanding.
- Focus on what is happening right now. Check for understanding.
- Discuss any changes they will experience. Check for understanding.
- Allow time for questions.
- Ask simple questions to check your child's understanding at each point in the conversation and especially at the end.

Realistic expectations:

■ Children process and cope through play. Expect children to want to engage in play or any normal activity during or after your conversation. Nonverbal outlets will be especially important for children who process best in this way — encourage these as much as possible.

Information will need to be repeated

 expect regular questions and plan
 to set up routine family meetings after
 the first conversation. Plan to include
 different age-appropriate activities
 that may promote conversation (See
 "Family Activities" in appendix for
 ideas.)

What if...

Emotions take over the conversation. Provide some time for emotions to be shared. If emotions are overwhelming, come back to the conversation later. It's okay to show your emotions. When parents show how they are feeling, this helps normalize typical emotions that all may share.

You are unsure how to respond to certain questions that may come up:

Unexpected questions: "Gosh, that's a great question. Let's think about that together..."

Big questions don't always need an immediate response. It's okay to say, "That's a great question – let's write that down. I'm going to think about it and talk to _____ (co-parent and/or doctor) and come back to that"

To help clarify a question: "Can you tell me more about what you are asking – are you asking how dad got sick?"

Your child isn't interested in talking about a medical situation. A child who is quiet at baseline won't typically become more talkative during challenging times. For children who prefer nonverbal methods of communication, some ideas may be to communicate basic information through a shared notebook or emails. It's important for these methods to be accompanied with time and space for open dialogue as well, especially to check how the child is understanding what has been shared.

Illness Education:

Children can benefit from specific developmentally appropriate information about an illness. Many resources can assist you depending on your situation. Additionally, illness or treatment related symptoms may greatly impact how you function as a person and parent. Helping children understand symptoms and why they are happening may promote coping and prompt help and cooperation.

Common symptoms may be extreme fatigue, pain, memory challenges, changes in appearance, lowered immunity, emotional imbalance, and others. Whatever symptom(s) you are experiencing, consider sharing these key points with your child and be realistic about how it may impact the daily plan:

Name the symptom and what is causing it.

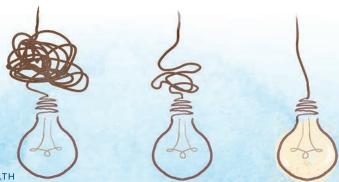
The chemotherapy medicine is making me feel very tired today.

Provide a child-friendly way to describe how the symptoms are impacting your body/ability to parent in the way you typically would.

My energy is like a car's gas tank – when I'm feeling good and have a lot of energy, my tank is full, and I can do all the regular things. When I'm low on energy, there just isn't much gas in my tank. I won't be able to play outside with you like we planned today.

Create a coping plan.

When I'm feeling so tired, I'll need a little bit more help from you. I'll need you to come home and finish your homework after school without me reminding you, okay? And if you need extra help, let's ask dad when he gets home.



Plan for activities you CAN still do together.

When I'm feeling tired, I would still really like to spend time with you. Can we make a list of activities to do together on my tired days? For starters, after your school work is done, maybe we can read together?

It's hard to know how symptoms will affect a family situation some days, so having family coping plans mapped out in advance can help. Collaborating as a family on these ideas is best so that everyone feels included. The main



message for any activity is focused time together – even when there is little energy to do much, there are ways to still feel connected.

Connecting with the School:

Many schools offer counseling and other supports for children. Depending on your child's grade and school environment, support options may vary. Regardless of the setting, sharing information with the school about your illness can be helpful for many reasons. Here are some strategies to consider:



Choose a point person:

- Choose the point person with your child; this person could be a teacher, principal, vice principal, counselor, nurse, or other.
- Share important information and updates with this person.
- Your point person can also relay valuable information about your child back to you or others at the school (e.g., child having a hard time focusing, not wanting to engage in typical activities, etc.).

Information to consider sharing with school:

- Diagnosis and basic information about treatment plan and any side effects
- What words are used at home to discuss information related to the illness
- What the child understands about the illness and how they are generally coping
- Plan for communicating information (e.g., once a week via email)
- Specific information sharing instructions for the point person. Do you want them to share information with other staff or do you prefer for information to be shared on an as needed basis?

General school-day considerations:

- Workload: A parent's illness can affect a child's ability to focus. Talk this over with school staff to decide what may be best for your child.
- Non-verbal signal: Creating a system where the child can have comfort items available and/or someone to talk to if needed will be helpful. A child and teacher may even want to create a non-verbal signal for the child to communicate this need.
- Script: Prepare your child for questions that may be asked about your illness. It's great to come up with a few responses they can use such as, "Thanks for asking. I don't feel like talking about that today" or "My dad is getting a medicine that makes his hair fall out, but it will grow back."
- Coping plan: There will be days that are harder than others. Creating a coping plan or a coping kit with your child for school may be helpful. A plan may review ideas related to support people, favorite places, coping strategies. A coping kit may include family pictures, comfort items, and a fidget item.

Prepare your child for questions that may be asked about your illness. It's great to come up with a few responses they can use such as, "Thanks for asking. I don't feel like talking about that today" or "My dad is getting a medicine that makes his hair fall out, but it will grow back."

When to seek more help:

Parents often wonder how to assess how their children are coping during an illness and if they should consider seeking additional support. Has your child's behavior changed since the illness?

- What is your child's general temperament like? If a child's temperament is somewhat challenging before an illness, this will not change after a parent's illness.
- Is your child able to engage in regular activities (e.g., family life, school, and friendships)? It's normal to have stress in at least one of these areas during an illness.
- Are earlier coping strategies no longer helping with this situation?
- Is the child trying to create a sense of control in other ways (e.g., relentless acting out, repetitive behaviors, etc.)?

If behavior isn't getting to a new normal that is manageable, persists for more than a few weeks and/or it's getting worse, connecting with a mental health professional for assessment and ongoing support will be best. Your child's pediatrician can help you start this process.

Parenting Support

Parenting is more stressful when life is not in balance. The following strategies may help you feel more stable and promote family coping.

Self-Care: Finding time for yourself —whether it is taking a walk, journaling, or something else — it is critical and requires extra attention. Focusing on your own needs can help you feel more grounded and better able to support your child. This may feel unnatural to you, though just as when you're in an airplane, in an emergency situation, you need to put your own oxygen mask on first before you can help those around you.

■ Maintaining routines: Routines provide all of us with a sense of security and represent a life that is normal and predictable. Creating a family calendar may be the single easiest way to keep everyone on the same page and involved in family planning. Upcoming events and any DAD'S SURGERY changes to the schedule can be added to the calendar, so everyone is prepared for what to expect.

Limit setting: When schedules start shifting due to a parent's medical needs, and/or a parent isn't feeling as well as normal, a child's limits and boundaries can blur. If parents aren't feeling up to

setting limits and children are feeling a greater sense of control when testing limits, things can get out of hand. Creating visual reminders (posted throughout the home) can help guide children and let other support people who are caring for the children know what the family expectations are.



■ Engaging children in a helping role: Having developmentally appropriate options for helping at home can give children a sense of control and a way to contribute that feels good and promotes coping. Work with your child to decide what ideas they may have for this - creating artwork for the parent's room or helping with small household chores.

Friends, play, and self-expression: Encouraging children to continue normal activities as much as possible will be positive and provide time for children to recharge.

Helping Children Visit the Hospital

When a parent is in the hospital, it can be hard to decide if and when a child should visit. Many factors go into this decision. The first is if the hospital or specific unit allows children to visit. Some additional questions to consider:

- How long is the hospitalization expected to be?
- How is the child coping with the separation from the parent?
- What is your child's age, developmental level, and temperament?

If the hospitalization is expected to be short and the child is coping well, a visit may not be needed, and you can instead think about fostering connection by:

- Regular phone calls or virtual visits
- Shared communication journal (with writing and/or pictures)
- Children creating pictures for hospital room

If you are planning a hospital visit, offer your child preparation before the visit. Relate this preparation to their senses — what will they see, hear, smell, and feel. If possible, show your child pictures of the parent and room environment so they can see in more detail what to expect.

It's also important to think about support during a visit. Let your child know how long the visit will be and what activities they can do while

there (e.g., "Mom will be wanting to rest during the visit, but you can sit by her on the bed and read to her..."). Bring supportive outlets to promote coping during the visit — coloring, reading, or any familiar activity.

After the visit, be sure to check in with your child to see how the visit went. Conversation starters might be, "One thing that surprised you about the visit was_____," or "The best part of the visit was_____," or "The best part of the visit was_____," If your child is upset after a visit, focus more on coping than on processing the visit. Honoring a child's desire to be silent is okay. Asking about something they may be looking forward to and then coming back to thinking about the visit is also okay.



Advanced Illness Considerations

For some parents, there may come a point where there aren't any treatment options left to prolong life. This is an incredibly hard situation to be in. There is no easy path forward though continuing to protect the relationship you have with your child by being honest is important. Here are some key points to keep in mind.

Timing for conversation: If children have been included in the medical situation from the beginning, they have a background for what is going on. Sharing with children how things are shifting early on helps them control how they spend what time they have left with the parent. They are also able to grieve change and loss with others and find the support they need.

Beginning a difficult conversation:

- Assess your child's understanding:
 What do you think is going on with the cancer in my body right now?
- Tell your story:

Remember how the doctor said that after the surgery, the chemotherapy was supposed to get rid of the rest of the cancer? Well, it's not working, and the cancer is spreading. I know, this is incredibly sad. At this point with my illness, there are no other medicines, surgeries or therapies to help.

Discuss changes the child may experience:



My body is going to start shutting down. Eventually, I'm going to die. They are going to give me medicine so that I'm not in pain and kept as comfortable as possible. These medicines may make me sleepy.

- Describe death in a clear way:
 - When my body stops working and I die, my heart will stop beating, my lungs won't need air and I won't be able to see, smell, eat or think.
- Offer time for questions and make a plan:
 - This is really hard information to think about. Let's take it day by day and start by making a list of things we want to do together:

End of life considerations: Many parents wonder what location is best as they are nearing the end of life. This is dependent on many factors though children typically cope best when included as much as possible, to an extent that they desire. When a parent is dying, offering children realistic choices in end-of-life planning is best.

Creating memories and leaving a legacy: Legacy includes the process of leaving something behind, including all of the intangible moments throughout life. You may want to create keepsakes for and with your children. This could be any activity that is personal to you and your family - like a family photo album, lists of the parent's favorite music/books/ movies, or a variety of creations together. Including your child in legacy activities gives them a sense of control in a very out of control situation. This is invaluable.

Funerals and ceremonies: Each family will have a different way of honoring the family member that died. Continuing to include children through this process can be helpful. Some children may want to contribute to the ceremony in some way. Others may choose not to be a part of it and celebrate their family member in another way. Preparing your child for what to expect and honoring their choice will be the best path.

For more in-depth support related to communicating with children about end-of-life circumstances and supporting them throughout, please refer to the UC Davis Bereavement Booklet (included in the reference section).

Closing:

Information included in this booklet is not exhaustive and is intended to help find ways to include and support children during a parent's illness. May this booklet live in your home library to be used as needed throughout an illness to navigate these times in your family, as a family.

Family Communication Activities:

Family mailbox:

Make a family mailbox using a jar or shoebox.

 Family members write questions, thoughts or ideas they are wondering about on strips of paper to be placed inside the mailbox.

 You can decorate the mailbox together.

 Thoughts and questions can be explored during regular family meeting times.

Shared family notebook:

- Find a notebook (lined or not) to begin a shared family journal.
- This can be a book to share thoughts and feelings through writing and/or drawing pictures.
- Questions can be written down for family members to answer or it can be a place to write freely about any thoughts/feelings.
- For younger children, it may work best to primarily use pictures to communicate information.

Thumb-ball:

 Find a beach ball or any ball that can be tossed around easily that you can write on.

Write prompts all over the ball. For example, some prompts may be: Something that cheers me up when I'm feeling sad... | A family activity I wish we could do more is... | If I had three wishes, I would wish for... | A question I have about my parent's illness is... (etc.).

 Toss the ball around to each family member and answer the prompt where a thumb lands.

 Keep the game going as long as all are engaged.



Family Coping Activities:

Family Coping kit:

- Find a bin or basket to create a "family coping kit."
- Search around the home for coping items that all can use when having trouble coping. Some ideas may be favorite books, simple activities, stress balls, bubbles, and any items that bring a sense of calm.



Regularly assess as a family how the coping kit is working for all and change out items as you see fit.

Favorite place collage:

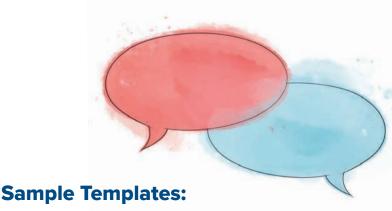
- Create a collage of your favorite place. This place could be a place you have been to before or one you are dreaming about.
- Find a piece of paper, glue, markers, and cut-outs from magazines.
- Glue cut-outs on the page or write in favorite places, things, people, about the place that helps bring it to life.
- This can be an individual activity, or a family can create a collective "favorite place collage."

Family Name Poem:

- Use your last name or other word that represents your family.
- Write the word on a piece of paper with room underneath or to the side of the word.
- For each letter of the word, think of a descriptive word that represents your family.



Steady Together Rowdy Orderly (sometimes) Nice Grateful



Most conversations are not as easy as 1-2-3; these scripts are general guides and go hand in hand with the information reviewed in the booklet. The scripts below represent a two-parent household; for one-parent households, aim to recruit a parent-like partner for these discussions.

Script: Dad's New Diagnosis | Parents and 7-year-old

Parent: "Mom and I wanted to talk to you about something important. I wasn't feeling well and went to see my doctor. My doctor, just like a detective, ordered some tests to learn more about how my body was working. One of the tests was to take pictures of my chest. With these types of pictures, they can see inside my body."

Child: "Did the test hurt?"

Parent: "It didn't hurt and the doctors and nurses took good care of me. The pictures showed that there is something in my chest – usually cells in our body help us think, run, play (etc.) but the cells in my chest are clumped together and aren't helping my body right now [a bunch of grapes can be a good visual for a cluster of cells]. The cluster of cells is called a tumor and the name of the problem is cancer. Have you heard of cancer before?"

Child: "No....and, how did the cells get there?"

Parent: "The doctor isn't sure how they got there but nothing you or anyone else did caused it to happen. And you can't catch this problem from me e.g., like you can catch a cold from other people. They are going to be taking really good care of me and I'll keep letting you know what's happening along the way."

"Okay, and for a mini pop quiz – how did the cancer cells get in my body?" [Checking the child's understanding.]

Child: "It was no one's fault and the doctor isn't sure how they got there."

Parent: "Exactly right. Do you have any questions right now? If any come up, you can talk to me or mom at any time or put them in our family communication mailbox."

[The next conversation may be about the plan moving forward – steps being taken to treat or manage the illness, possible side effects, and any changes related to energy level, mood, or appearance. Using pictures, especially with younger children, can be helpful to promote understanding and elicit more questions.]

Script: Change in Illness Course | Same parents and 7-year-old

Through sharing updates, children will continue to have background for the situation and be able to share in the family processing:

Parent: "Hey, it's Friday afternoon – our regular family meeting time. I wanted to share some more about how things are going with my cancer treatment. Are you ready to meet now or do you need a few minutes?"

Child: "Let's meet now as long as I can continue doing my coloring while we talk..." [It is okay and can even be beneficial for children to have an expressive outlet in motion during conversations that may be more difficult.]

Parent: "Feel free to keep coloring. So, remember when the doctor said I needed to have more pictures of my chest taken? They wanted to see if the chemotherapy medicine I've been taking has been working to get rid of the cancer cells."

Child: [Continuing to color...] "Okay..."

Parent: "The doctor let me know that the cancer cells started spreading to other parts of my body. This wasn't what we were hoping for. The doctor is going to try a different treatment plan that they feel may be more helpful - I will start this next week."

Child: "Why did the cancer grow in other areas?"

Parent: "I keep wondering about that. Sometimes things happen that are out of our control and it's hard. I'm going to try to stay positive, but I'm also feeling mad, sad, and frustrated. It's okay to have a lot of different feelings right now; it's hard not to have all the answers. When I'm feeling really upset, I start by taking three deep breaths – can we do that together right now?

I'll keep letting you know how things are going each week and if you have questions that come up at any time, let me know. Do you have any other questions right now or do you want to take a break from this and go outside and play?"

Child: "I'll race you to the swings!" [Very normal for children to want to take in hard information in small doses, so incorporating play into these meetings can promote coping and processing.]

As you move forward, keep the conversation going and regularly check in about the frequency of information sharing (too much, too little, etc.).



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Child life specialists partner with families during a parent's illness to create care plans that meet the psychosocial and developmental needs of each child. Primary goals are to promote continued family communication, coping and connection. These services are available throughout adult units in the hospital and within the Comprehensive Cancer Center.





COMPREHENSIVE CANCER CENTER

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For more information, please visit: ucdavis.health/childlife