



BC PROVINCIAL
Pediatric Oncology
Hematology Network

Newsletter



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EXPANDING YOUR PEDIATRIC TOOLBOX: A GUIDE FOR COMMON CHALLENGES IN CHILDHOOD CANCER:

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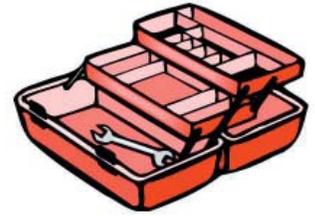
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This guide is compiled and developed based on the group discussion at the November 2005 Pediatric Oncology Cancer Conference and our research in each of the four areas addressed:

1. Explaining Cancer to Children and Other Terminology
2. Helping Children Manage Pain
3. Helping Children Face Needles
4. Helping Children Take Medication

Within each topic, you will find a description of the main issues identified, suggestions to consider,

and specific strategies that have been found helpful in each age group, including preschoolers, school-aged children, and teens. In addition, we have included at the end of each section suggestions of resources that you can access easily for more information and education.



EXPLAINING CANCER AND OTHER TERMINOLOGY TO CHILDREN



When the word "cancer" enters a family's life, parents cannot protect their children from the language of cancer and the associated treatment. As parents and health care professionals it is important that we are thinking and rethinking about how we talk to children about cancer. At the time of diagnosis there is no certainty. It is then reasonable to treat each child as a survivor. The goals of our interactions with children work towards foundations that are for a lifetime:

- To foster normal growth and development
- To promote adaptive family functioning despite the difficulties, and uncertainty

- To foster healthy, trusting relationships with significant adults including parents, doctors, nurses and other health care professionals

The key to achieving these goals lies in our relationship with the child. Our relationship with the child and his/her sibling(s) usually starts with the word "cancer". Therefore, how we explain cancer is very important.

Key:

- Two-way communication - eg. parent checks in with the child about what it is he/she understands; assesses how he/she is perceiving information. A relationship is fostered with the child to encourage them to "check in" with the parent regarding possible misunderstandings, fears, etc. Children can be protective of their parents/significant others and may not express their fears or negative

feelings. Teens can misunderstand information or receive inaccurate information from peers. It is important that parents/significant adults demonstrate a willingness to engage in open, honest conversation with the child. Think about asking questions to assess the child's understanding as you provide answers and information so that you are collaborating together.

- Honesty – this includes saying "I do not know"
- Age/developmentally appropriate language and pace:
 - Encourage parents and caregivers to go slowly and not flood the child with information. Just as adults need time to adapt to what happens so do children and teens
 - Respect the child's means of controlling information overload eg. changing the subject, turning on the television, etc.
 - Remember that this is not a one time conversation; new information tends to be absorbed in "layers"

AGE SPECIFIC STRATEGIES FOR EXPLAINING CANCER AND OTHER TERMINOLOGY TO CHILDREN

Preschoolers: age ≤5 years

- Concrete thinkers
- Link events to one thing, i.e. their experience, eg. usually visualize illness or being sick as staying in bed or eating chicken noodle soup
- Understand concepts like "good" and "bad"
- Able to understand metaphors like good healthy cells, bad cancer cells and the medicine called chemotherapy which helps fight the bad guys
- Can link with familiar ideas, eg. germs are bad, cancer cells are bad cells
- Have magical thinking
- Egocentric - the world revolves around them; have difficulty seeing things from different perspective; see themselves as responsible for what goes on around them
- Need extra reassurance that they did not cause the illness; that the illness and associated treatment is not punishment for something they did wrong; that it is not their fault that people i.e. mommy/daddy is upset and crying etc.
- Use models, games to explain cells, cancer cells, chemotherapy; very simple pictures, dolls, and body books



School Age: age 6-11 years

- Less likely to believe the illness is because of something they did wrong; although may still appreciate reassurance from parents/health care professionals
- Limited in their own experience but starting to understand the relationships between events: sickness -> medicine/treatment, sickness -> symptoms
- Able to understand more detailed explanations of cancer because they are better able to understand interrelated parts:
"Your body is made up of millions and millions of cells. These cells are like building blocks that work together to help your body do all the things it needs to do. When you have cancer, some healthy cells get out of control and change into sick cells. These sick cells push your healthy cells out of the way. They become strong, grow, and spread into the rest of your body. When sick cells clump together, they make a lump in your body. This is called a tumour. Sick cells stop your body from working the way it should; that's why you feel tired and achy."
Or more simply:
"Different cells in the body have different jobs to perform; cancer cells are like the trouble makers that disrupt the healthy cells from doing their job(s). The treatment, chemotherapy, is to get rid of these trouble makers."
- Use models/diagrams, games, to explain cells, cancer cells, chemotherapy; also body books to explain the location of the disease, how the body works etc.



Teens: age 12 years+

- Are better able to understand complex relationships between events; they are more likely to think about things they have not experienced themselves
- Define illness by specific symptoms such as tiredness and the limits on everyday activities; they are also better able to understand the reasons for their symptoms in the context of the disease:
"(ALL) blood is made up of 3 parts each with a unique job: red blood cells, white blood cells, and platelets. Because the cancer cells replace normal cells in the bone marrow, there are fewer platelets and this is the reason you may bruise or bleed more easily etc. The goal of treatment is to kill cancer cells; and then the body can function normally and the symptoms will go away."
- Use visuals: CT scans, MRI scans, models/diagrams etc.



RESOURCES

Books

Explaining Cancer to Children of All Ages: What is Cancer Anyway? Karen Carney (1998)

You and Your Cancer: A Child's Guide
BC Decker Inc (2001)

Talking with Your Child about Cancer
Canadian Cancer Society (1993)

Websites

For brain tumours: www.abta.org/kids/home.htm

For parents: www.curesearch.org

There is an excellent section on this website about effects of illness on different ages/stages of a child's life

For school aged children:

www.royalmarsden.org/captchemo/adventures.asp

For teens: www.teenslivingwithcancer.org
www.planetcancer.org
www.2bme.org

HELPING CHILDREN MANAGE PAIN

Pain in childhood cancer may come from several sources including pain from disease, pain from procedures, and pain from cancer treatment. Effective pain management is best achieved using a team approach that includes the child, parents, and health care professionals. We begin by acknowledging that great advances have been made in pain medication for children, that the efficacy of pharmaceutical approaches is well-established, and that medication is often integral to pain management in childhood cancer. In this discussion, we refer to strategies for pain management that are intended to COMPLEMENT and NOT SUBSTITUTE appropriate pain medications. Although we do not include medications in this discussion, we are NOT advocating against their use. Our goal is to draw attention to other aspects of pain management that the child and parent can practice either individually or together.

Pain Scale



General Strategies:

- Understanding pain from the child's point of view is critical to achieving good pain management and is an ongoing process. In your pain assessment, acknowledge the pain immediately and inquire specifically about it.
- Inquire about the non-painful body parts to get a sense of the child's whole experience; this may also help identify strengths.
- Pain is an isolating experience and this in turn can be frightening particularly in the case of acute pain. Ensure that the child is not left alone until the pain is under control. Even for teenagers, the physical presence of a parent or staff counts for a lot.
- Be aware of the use of language
 - Your choice of words and tone matters, not only during the pain assessment, but also (especially!) during the application or instruction of pain management techniques
 - Opt for neutral rather than loaded words that can heighten sensations of pain (eg. "episode" instead of "attack")

- Avoid statements of confusion and uncertainty (eg. "*this pain is mysterious*" or "*I don't know what's causing this*") that may induce fear and undermine the child's confidence in you
- Tell the child what positive steps have been taken or will be taken to deal with the pain
- Provide hopeful messages whenever possible
- Draw from the child's own experiences and interests to ensure the metaphors you use are comforting
- Practice these methods yourself to ensure that you are calm, comfortable and effective as a model for the parent and child
- Consider teaching techniques to parents to ensure their collaboration and their good coping
- Encourage parents to practice methods they enjoy and that make them feel better
- Never use medical procedures as a threat
- Give some control to the child; the feeling of being in control is known to reduce sensations of pain
- Keep clear notes on what works well for each child so that other team members can be consistent

Techniques to be used as an adjunct to and not a substitute for pain medication

Specific Strategies:

The following is an overview of adjunct pain management strategies. Some are intuitive and others require training and practice. Please refer to the resources at the end of this discussion for a more complete description of these approaches.

Psychological Methods

These exercises often require some instruction and coaching and ideally should be learned in a state of relaxation; ie. ahead of time before the pain episode is expected to take place. Children and parents are encouraged to practice them regularly; they can be easily incorporated into a self-care ritual and need not take a huge amount of time to work.

- Distraction techniques work especially well for short, acute pain
- Comfort measures including a quiet presence, music, a warm bath, rocking, touching (rubbing the injury and/or gently stroking elsewhere) are helpful for both acute and longer

lasting pain; breathing the pain away is also helpful

- Relaxation and imagery in combination with breathing techniques are helpful with persistent, achy pain; as children get older, they may require explanation as to how these strategies work to ensure full participation and maximize benefit:
 - they are helpful in reducing anxiety and tension that make pain worse
 - anxiety stops the brain from blocking the feeling of pain
 - anxiety can also increase pain by essentially opening pain "switches"
 - anxiety uses up needed energy, decreases rest and sleep, and tires the child, making it all the more difficult to cope with pain
- Self-talk – this can be calming and helpful for some children, whereas for others it increases anxiety. Examples are "*This will be over soon*", "*I can handle this*", "*It's tough but I'm doing pretty good*"

Physical Methods

These may be best taught by a physiotherapist or occupational therapist, and their application should be discussed with medical staff.

- Heat and cold (compresses/pads or packs) may help relieve some pain but require caution to avoid accidental burns or freezes. Ice packs should be wrapped and their application closely monitored (eg. no longer than 10 minutes); they should NOT be used immediately after chemotherapy injection since it will change the absorption of the drug
- Transcutaneous Electrical Nerve Stimulation (TENS) may be very useful for "phantom" pain following an amputation
- Massage is effective for all types of pain and may be especially helpful for spasms
 - like imagery, gentle massage with affectionate touch of non-painful areas provide a pleasant experience that will compete with pain



AGE SPECIFIC STRATEGIES FOR HELPING CHILDREN MANAGE PAIN

Pre-Schoolers: age ≤5 years

- Distraction techniques:
 - for babies: “motherese” and dramatic talk with babies, show them something bright and moving
 - for preschoolers and early school-age: blowing bubbles, party-blowers, pop-up books, singing songs, reading favourite stories, puppets
- Cuddling
- Relaxation: being a wet noodle, flopping like a Raggedy Ann doll
- Control: simple choices between two things, eg. sitting on a lap vs. a chair, which finger to get pricked, whether to wear a band-aid



School-Age: age 6-11 years

- Distraction: conversation, pleasant memories, I SPY books, story-telling
- Self-talk during a procedure can be coached in children 6 years and up (eg. “I can handle this,” “This will be over soon”, or “I’m doing really well”); after age 10 children can use self-talk even when a “coach” is not there
- Comfort items (favourite or “lucky” items)
- Music or stories on tape
- Relaxation – Raggedy Ann doll, wet noodle for younger children; 10 years+ may be able to learn formal muscle relaxation
- Pleasant imagery (favourite activities, going to a safe place, magic carpet ride)
- Control



Teens: age 12 years+

- Distraction: conversation about past, present, or future events; listening to CD’s or walkman
- Problem-solving: older children and adolescents can engage in brainstorming and learn what makes their pain worse and what makes it better; self-monitoring/logging, ie. keeping a record of the pain on a calendar can be helpful for problem-solving discussions
- Self-talk: older teens can learn a more sophisticated strategy called A.D.A.P.T.:
 - Acknowledge the negative feeling or thought
 - Describe what statements or thoughts are causing the negative feeling
 - Assess if the thoughts are helpful
 - Present alternatives to the thoughts
 - Think praise: give yourself a pat on the back for a better way of thinking
- Muscle relaxation combined with slow, belly breathing and imagery
- Control



RESOURCES

Books/Videos:

“A Child in Pain” – a great resource for parents and staff, written by Dr. Leora Kuttner

“No Fears, No Tears” – a video also featuring Dr. Kuttner and children of different ages mastering various pain management techniques

Websites

<http://pediatric-pain.ca/mclp/mclp.html>

Can also go to Google and type in ‘Making Cancer Less Painful Handbook’ – this is an excellent, user-friendly site that gives parents clear information as well as suggestions and guidelines on how to help their kids manage pain. It also describes well-known strategies for children of different ages and gives concise explanations of when and why they are helpful. There are even examples of relaxation scripts for parents to try with their youth. Parents have access to the complete Handbook, and can print off the sections most relevant to them.

<http://www.childcancerpain.org>

This is posted as “an educational pain management resource for health professionals who care for children suffering from pain due to cancer” but may also be of assistance to parents.

<http://www.caringbridge.org>

A website that promotes communication between families and friends and that helps broaden social support networks.

HELPING CHILDREN FACE NEEDLES

Dealing with needles on a regular basis is a significant source of stress for children and teens. While our general goal is to make the experience as positive as possible, it is important to remember that some anxiety is normal. We need to convey this message to our children by letting them know that their fear, crying, etc. is understandable and then work with them to try to create a plan that may help minimize their pain and anxiety.

Preparation for Procedures:

- choose the right person to accompany the child; parents need to manage and check their own anxiety levels (ie. not an overly anxious or needle phobic parent)
- find out what is the "norm" for this child – what has worked before & recreate that experience as closely as possible; keep a routine. Try to meet with parents/child ahead of time to determine their wishes or ask other staff who have worked with a particular child
- remember that the experience is important to the family – it is not just another needle for them
- determine if child is an attender or avoider – do they want information or would they prefer to not talk too much about it or not see the needle coming
- be honest so the child knows exactly what to expect. Explanations should be brief but accurate; parents should ask this information of staff so they can explain to their child
- provide visual demonstrations of the equipment and tools, medical play

- tell the child why the procedure is necessary
- teach parents how to help their child
- ask the child if they have a particular strategy that works for them
- get the child involved in a solution: *"Since we've got to get this blood test, how can we work together to make it as easy as possible?"* Even very young children can brainstorm. When they are involved in coming up with a solution, they try harder to make it work. When brainstorming, give option to child of who he/she wishes to be present during the procedure
- do everything you can to get the child to relax; eg. leave plenty of time to get to the lab (If you are tense in traffic, your child will get tense, too; play soothing music in the car on the way to the lab; make it a one-on-one time with the child who is getting the test, leave siblings with a sitter)
- practice strategies prior to the procedure; don't expect to just figure out a strategy in the moment
- use a numbing agent such as EMLA; ice before and after

During Procedure:

- keep environment calm
- take your time, don't feel rushed
- use relaxation techniques and deep breathing. The use of bubbles encourages deep breathing with children



- use distraction (ie. puppets, stories, video games, music, video, I Spy books, etc.)
- use "magic glove", visualize magic glove that doesn't feel pain, or other visualization techniques. Note: these procedures require practice prior to the procedures and generally the help of a specialist (ask child life or psychology for ideas)
- use medication if necessary
- let the child know that you accept his or her emotions. Don't say, *"Now it's time to be a big girl."* Instead say, *"I understand why you are angry or upset."*

After-Care:

- release tension after the procedure by specifically shaking tension out of body part affected
- review with the child how he/she felt the procedure went and any ideas they have for making things go better next time
- provide special treats or awards for having gone through a difficult procedure (Note: child should receive the award for having gone through the procedure, not based on an evaluation of their "performance" during the procedure)

For Needle Phobics:

- may need specific interventions outside of medical procedures, make referral to child life or psychologist

BC CANCER AGENCY 2006 ANNUAL CONFERENCE NOVEMBER 23-25, 2006

PEDIATRIC ONCOLOGY DAY

SATURDAY, NOVEMBER 25, 2006

This year's pediatric oncology education day will focus on the latest in childhood leukemia and issues surrounding care for these children. For more information and to register, please go to the conference website:

<http://www.bccancer.bc.ca/HPI/ACC2006/default.htm>

Objectives:

- To enhance clinical skills and knowledge about childhood leukemia and care for the child & family
- To strengthen community partnership and improve communication within the provincial network

Time	Session
0830-0915	Pediatric Leukemias - Principles of Treatment
0915-1015	Complications from Leukemia Therapy
1015-1045	Break
1045-1130	Blood & Blood Products Transfusion Therapy
1130-1200	Relapsed ALL - Cure or Palliation
1200-1300	Lunch
1300-1400	Communication & Cancer
1400-1600	Strengthening Partnership in Care
	Child Health BC
	Community Care for ALL Patients
	Round Table Discussion

AGE SPECIFIC STRATEGIES FOR HELPING CHILDREN FACE NEEDLES

Pre-Schoolers: age ≤5 years

- determine what language works best for the child and is the least scariest
- decrease the anticipation time
- provide child with fun band-aids and rewards
- use distraction – bubbles, watch TV
- have parent hold child if this calms him/her
- use nursery rhymes, lullabies, massage techniques (prior, during, and/or after procedures)
- allow the child to move & run around after a painful procedure
- compare the amount of time the procedure will take to something that the child knows (ie. shorter than a TV commercial)
- count to 3 or give a warning so the child can prepare for when it is happening



School-Age: age 6-11 years

- provide child with fun band-aids and rewards
- give control over some details of the procedure; eg. ask what they would like to bring or do during that time
- give bravery certificates
- let them play Playstation, watch TV, etc.
- use relaxation and visualization techniques
- allow physical movement after the procedure



Teens: age 12 years+

- give more control (ie. option of pushing fluid quickly or slowly)
- let them play Playstation, watch TV, listen to music on headphones, etc.
- ask them for input
- use relaxation and visualization techniques



RESOURCES

Books/Videos

"A Child in Pain" – a great resource for parents and staff, written by Dr. Leora Kuttner

"No Fears, No Tears" – a video also featuring Dr. Kuttner and children of different ages mastering various pain management techniques

Websites

http://www.onconurse.com/factsheets/coping_child_procedures.html

<http://www.sickkids.ca/kidshealth/spring05vol6issue1/bloodwork.asp>

HELPING CHILDREN TAKE MEDICATION



Learning any new skill or establishing a new childcare routine can be a lengthy and challenging exercise for parents and children. Even

general tasks such as brushing teeth or establishing a smooth bedtime routine can be a frustrating time for children and a humbling experience for parents. Like all other aspects of childcare the advice is easier to dispense than to carry out. There are many factors that affect how children learn and adapt to new behaviors:

- age
- developmental level
- personality
- coping style
- temperament

- understanding and acceptance of the purpose of the activity
- desire for control
- parent-child relationship etc.

In the event of a cancer diagnosis and the need to establish medication routines or to learn to swallow pills, there are additional factors:

- ability to swallow easily
- fears or history of choking
- food or texture aversions
- unpleasant taste of some medications
- side effects of some medications
- diagnosis-related emotions, such as anxiety, anger, and denial

Discussing these factors is a starting point for assessing a child or teen's unique history and experiences related to the challenge of taking medication. General questions about how the

child adapts to any new changes or how they established other essential routines will give valuable information for tailoring strategies for establishing medication routines.

The following tips and suggestions can help make medicine time and pill swallowing easier. You will note that there is some conflicting advice in this information. This is because different techniques work for different people and there are different educational and parenting approaches. For example, there is debate over the use of reward systems, such as sticker charts and other tokens as a way of establishing new behaviors. While some parents and professionals routinely use this method to introduce new behaviors, others warn that these techniques can cause long-term problems for short-term gain.

AGE SPECIFIC STRATEGIES FOR HELPING CHILDREN TAKE MEDICATION

Preschoolers: age ≤5 years

- use liquid instead of pills
- use a spoon instead of syringe
- mix with something good tasting; eg. pudding, yogurt
- use health care play; eg. giving medicine to a doll or using puppets
- pick and choose your battles; eg. give IV or NG short term
- provide support for parents by modeling and teaching; finding out the child's previous experiences; have parents demonstrate and practice before discharge; give phone support when at home



School Age: age 6-11 years

- use liquid instead of pills
- establish a consistent routine around pill taking
- find the right route: liquid, pill, NG, etc.
- pill training with pharmacist
- crush and put in gel caps
- have someone other than the parent do the medication teaching
- use praise and other reward systems
- help the child understand the reason for taking the medication
- have the child practice swallowing pieces of cooked macaroni, then later put a pill in the macaroni (this idea originally came from a 6 year old!)



Teens: age 12 years+

- pill training
- acknowledge issues and challenges of wanting control
- manage side effects of medication



RESOURCES

1. Just a Spoonful of Sugar Brochure

This is a very useful brochure produced by Seattle Children's Hospital and can be downloaded at www.seattlechildrens.org/child_health_safety/pdf/flyers/PE398.pdf

2. Association of Cancer Resources Online

www.acor.org/diseases/ped-onc/treatment/Pills/pills.html

This is an excellent oncology-specific website reference for parents. It includes brief anecdotes from parents talking about their experiences and strategies. It provides reassuring and realistic information and peer-support.

One of the best tips from this website is to tilt your head forward, put the pill in the mouth, sip some water and swallow. By keeping the head forward the pill floats to the back of the mouth and the throat remains open.

3. Teaching and Maintaining Pill Swallowing Study

www.medscape.com/viewarticle/410255

This is a must-read article about teaching children to swallow pills by Czyzewski et al. This research study involved a systematic behavioral teaching program for children with HIV to learn how to swallow large pills. The teaching method is described in detail and involves the teaching methods of shaping (learning simple to most complex tasks which in this case was swallowing a sprinkle-sized placebo to increasingly larger placebos) and modeling (the trainer would also demonstrate the pill swallowing). The article emphasized the importance of having a "neutral" trainer for the child, not a parent, medical caregiver or other authority figure.

The trainers offered no extrinsic rewards during the training other than stating, "You did it!" when the child successfully swallowed a pill. The authors cautioned about "inadvertently reinforcing bad pill swallowing habits (coercion, bribery, intermittent non-compliance), although at times immediate success may seem very desirable." This was a theme of the article and they reiterated that, "Parent and non-behavioral health care providers tend to focus on attaining compliance at the moment, even if it requires substantial cajolery, bribery or punishment. However, they may neglect the long-term problems that their immediate solutions can cause." Their definition of successful pill swallowing learning was if it was "independent of any tangible reinforcement."

A video about this technique can be downloaded from www.baylorids.org under educational resources.

The Provincial Pediatric Oncology/Hematology Network

The Network is an interdisciplinary organization whose goal is to ensure appropriate diagnosis, management, follow-up, and end-of-life care for pediatric patients with malignancies and blood disorders.

The Network supports community hospitals and practitioners, and develops partnerships with other health care facilities to enable seamless and integrated care for patients and families on treatment and off treatment.

It will further develop and enhance the research programs of basic, translational, and clinical research to better childhood cancer control and improve outcomes for these patients and their families.

For More Information

To learn more about the Provincial Pediatric Oncology/Hematology Network, or to submit articles or stories to this newsletter, please contact:

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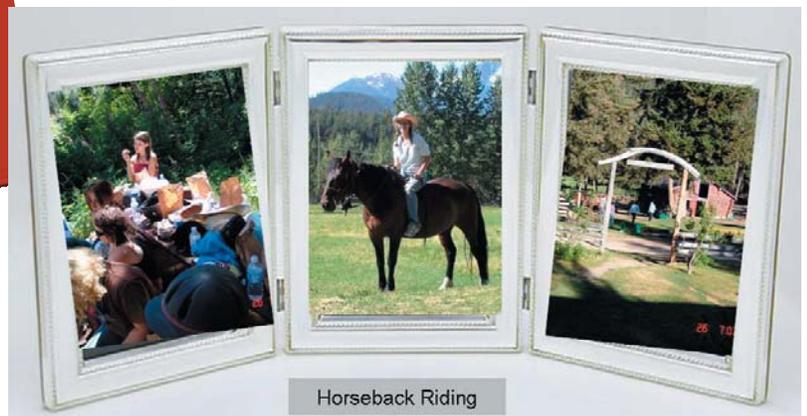
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TEEN ADVENTURES SPIRIT QUEST 2006

Scrapbook pages from this year's Teen Adventures.

Activities included:

- Surfing, kite flying and beach combing in Tofino
- Kayaking in Clayoquot Sound
- Horseback Riding in the South Chilcotin Mountains
- White Water



All activities are sponsored by the Oncology/Hematology/BMT Department through Balding for Dollars.

For more information about Teen Adventures - Spirit Quest, please contact the following:

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