

Hear My Voice



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Acknowledgement

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Alberta **Children's** Hospital



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Hear My Voice

A Note to Parents/Guardians

Hear My Voice is an activity to encourage you and your family to explore thoughts, feelings, values, and attitudes about the decisions you face as a family about your child's health condition and your choices for care along the way.

The decisions ahead are hard ones, and the answers are not easy or clear. There is no right or wrong answer. There is only **your** answer, the answer that comes from your mind and your heart. **Hear My Voice** is one of the ways you can start to explore your choices as a family. This is just one of many talks your family may have.

Hear My Voice is an activity to encourage talking within your family. You may also hear it described as a game. Using the word game does not mean that this is a playful or easy activity. Rather, the word game is used to fit the language of children and to make the exploration less scary for the child or youth.

In addition to this activity, there is also a Hear Our Voice workbook available at <http://www.albertahealthservices.ca/advancecareplanning.asp>.

Before You Begin: Suggestions from Professionals

- Read the questions on each card and review the "Tougher Stuff" category. If you decide that you are not ready to tackle some of the cards at this time, simply remove them from the activity.
- You know your child and family best, the cards have been written using general language (i.e. condition and illness experience) but you can change the words to fit your situation or to make it more easily understood by all family members
- There is no right or wrong way to answer these questions
- Adapt this activity in a way that works for you and your family, perhaps just selecting one card each day to use as a discussion point
- The most important part of this activity is simply the opportunity to ask questions and discuss your unique situation.

Hear My Voice

A Note to Professionals

The goal of the Hear My Voice activity is to encourage families to talk about their values and goals related to their child's health condition. The activity is intended for use with families who are coping with an illness to guide decision making during the illness experience. As a professional, you may be asked to take part in the activity, or the family may prefer to do this on their own.

Considerations:

- Has the team determined that this is an appropriate time for a discussion regarding health care choices?
- Does the family have the medical information they need for this discussion?
- Are you the "right" team member to approach the family? Have you known the family long enough? Is there a primary care team member?
- Is there another team member who could do the activity with you?
- Have you seen any communication styles within the family that would help or hinder this discussion?
- Does the family have the time, energy, and capacity to engage in this activity?
- Are there siblings who should be included in the discussions?

- Is the Hear Our Voice workbook an additional or alternate resource for this family?

Suggestions From Families:

Parents have reviewed this tool and have made some important recommendations that we would like to pass on to you.

- Be cautious of using the word "game" or "play" and whenever possible, refer to the tool as an "activity"
- If possible, ensure that you set up a supportive "space" for the family that allows for privacy
- Consider the family's energy and whether they are being encouraged by the healthcare team to participate in decision making.

Conversations:

This activity is meant to be one part of a larger discussion. It is not meant to serve as the sole tool for decision making, but rather as a tool that can be used as way of informing this process. Keep in mind that this is the beginning of many discussions that will occur over time and that a decision made today will often change as the illness progresses. This is normal and to be expected. It may be helpful to encourage using the activity at various points along the illness trajectory. As a healthcare professional, you are responsible for communicating the information you gather from the family to the healthcare team. Please remember to follow the standards of practice within your profession and your organization about documentation and communication.

Hear My Voice

Instructions

The **Hear My Voice** activity can be used in many situations. You can be creative in how you use the cards as there is no right or wrong way to move through these important and challenging questions.

Game Set-Up:

- Ask players to sit in a circle or at a table where they can see all cards
- Separate out the **Warming Up** and **Wrapping Up** cards and place in piles on the table
- Separate the **Signal Cards** (Stop, I Pass, This is Important, Everyone Answers, Ask Me Later...) and place on the table so all players can see them
- Deal one "?" card to each player
- Separate all remaining cards into categories (body, people, feelings, meaning, tougher stuff) and place face down in piles on the table

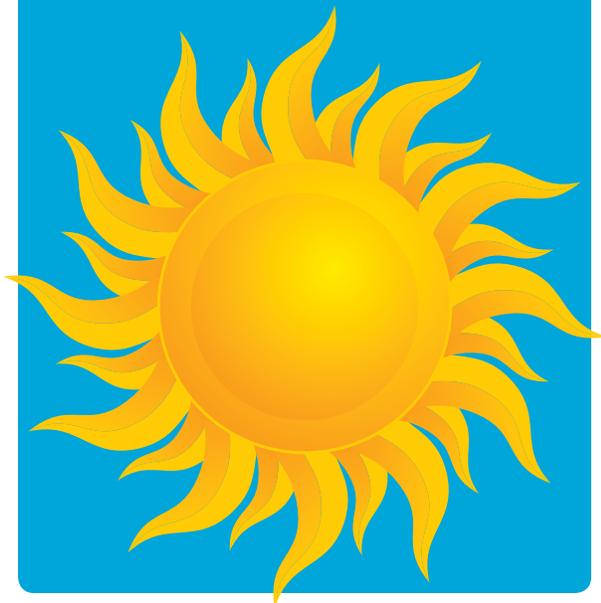
Instructions:

- The game begins with the **Warming Up** cards and always ends with the **Wrapping Up** cards (even in the event that the **Stop** card is played)
- The **This is Important** card is either held up or pointed to by a player sharing something that is very important,

is new information, or is something the player has felt misunderstood about in the past

- The **Everyone Answers** card is either held up or pointed to when a player would like other family members to answer a question that has just been read
- The **I Pass** card can be played any time a player does not wish to answer a question
- The **?** cards are blank and can be used to ask any question a player might have
- The **STOP** card is played when a player wishes for the game to **END** at which point players complete the game by answering the **Wrapping Up** questions
- The **Ask Me Later** card indicates that the player would like a bit more time to think about the answer or perhaps would like to talk to someone privately at a later time
- Players take turns selecting and answering questions
- Players can decide on rules for taking turns (eg. Clockwise)
- Starting with the **Warming Up** cards, players take turns by selecting a card, reading the question aloud, and answering the question. Cards are then placed in a discard pile
- Once all the **Warming Up** cards have been read, play continues by players taking turns selecting cards from the different categories and selecting which question they would like to answer
- Make sure that players know that the questions on the cards progress from easy, more challenging to most challenging
- The game ends when all questions have been asked or if a player wants to stop

Warming Up

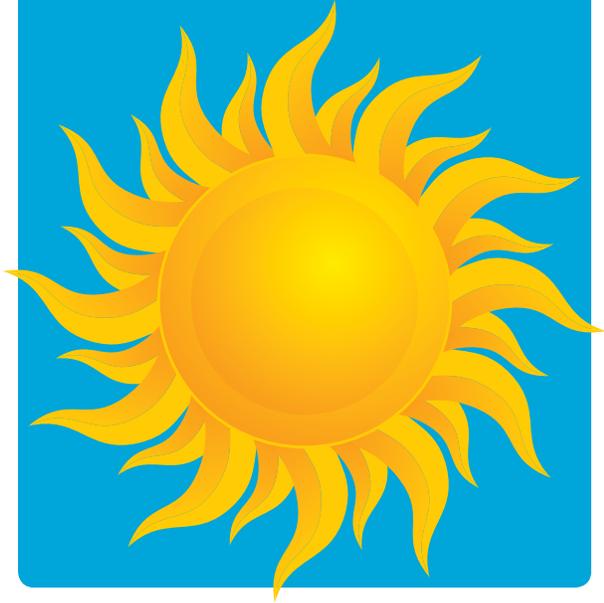


WARMING UP



If you could plan a perfect day with your family, what would it be?

Warming Up

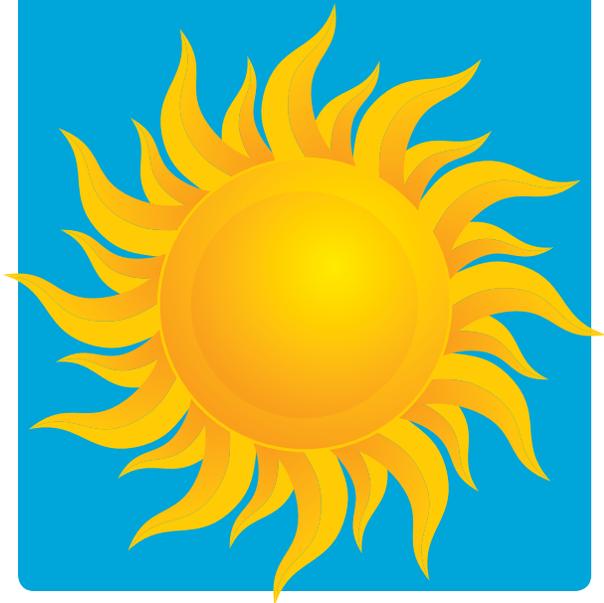


WARMING UP



If somebody were to do something really nice for you, what might it be?

Warming Up

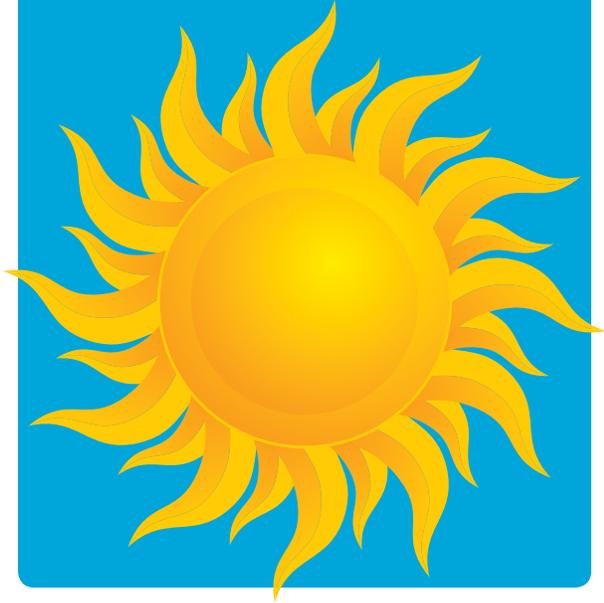


WARMING UP

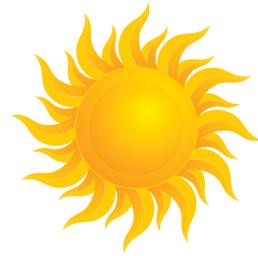


Tell us something you are proud of.

Warming Up

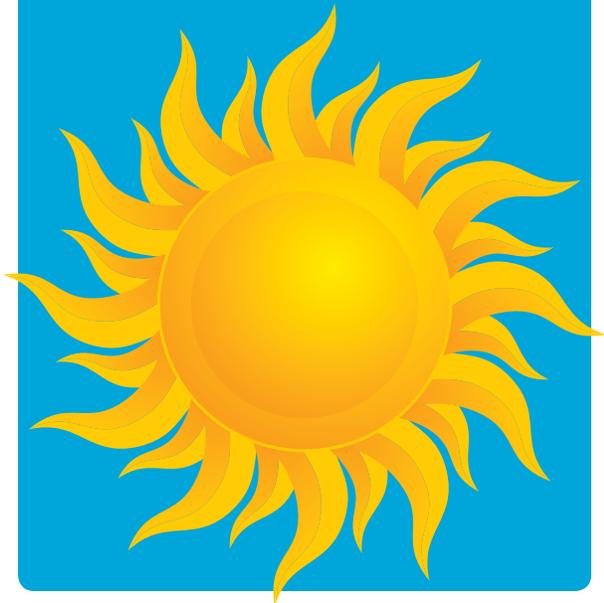


WARMING UP



What are the kinds of games or activities that you like to do with your family?

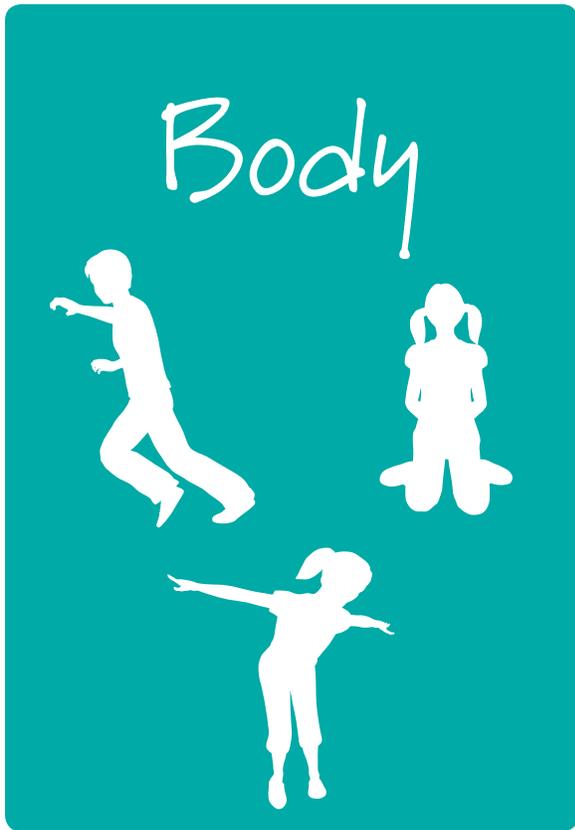
Warming Up



WARMING UP



Introduce each of your family members.

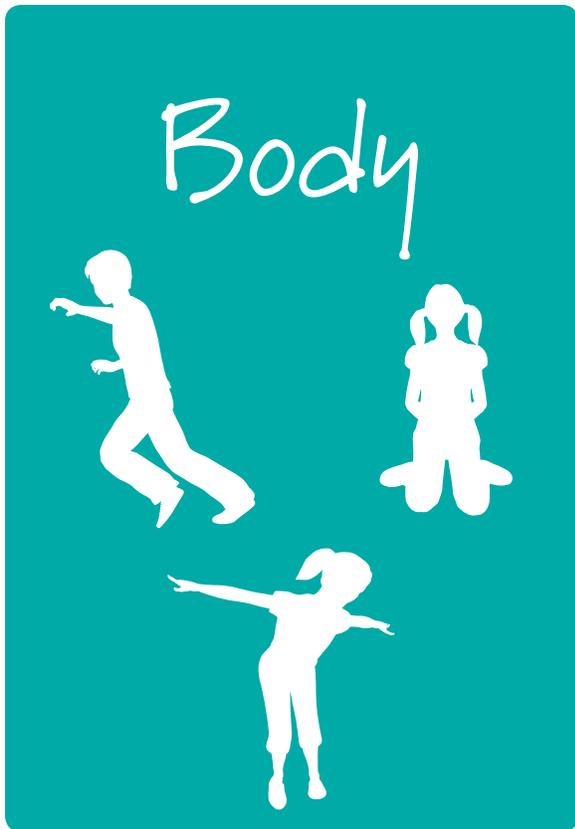


BODY

 How do you show others when you are in pain?

 Are there things that make you feel better when you are in pain?

 Talk about a time when you were in pain and something happened that was helpful. What kinds of things are not helpful?

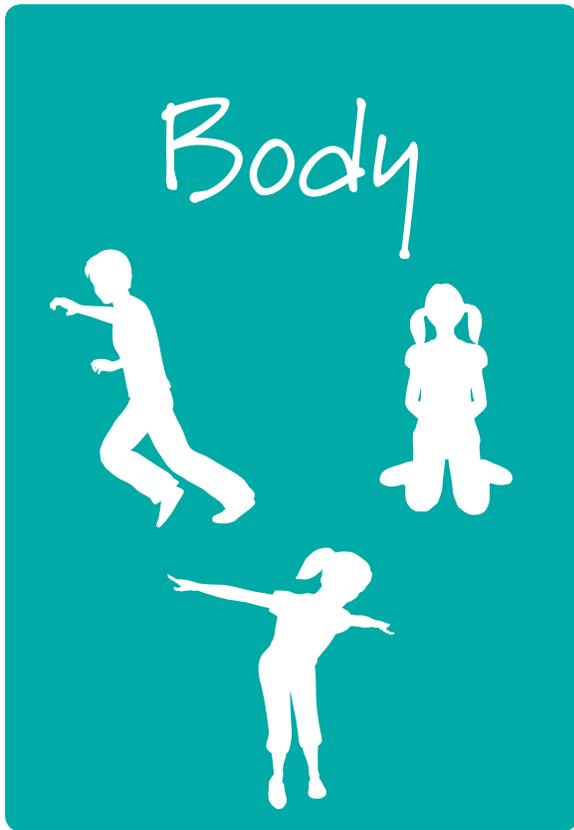


BODY

 Who do you go to when you have questions about your body?

 What is helpful to know about the changes happening in your body?

 If you are wondering about the condition, who do you go to with your questions and/or where do you look for answers?



BODY



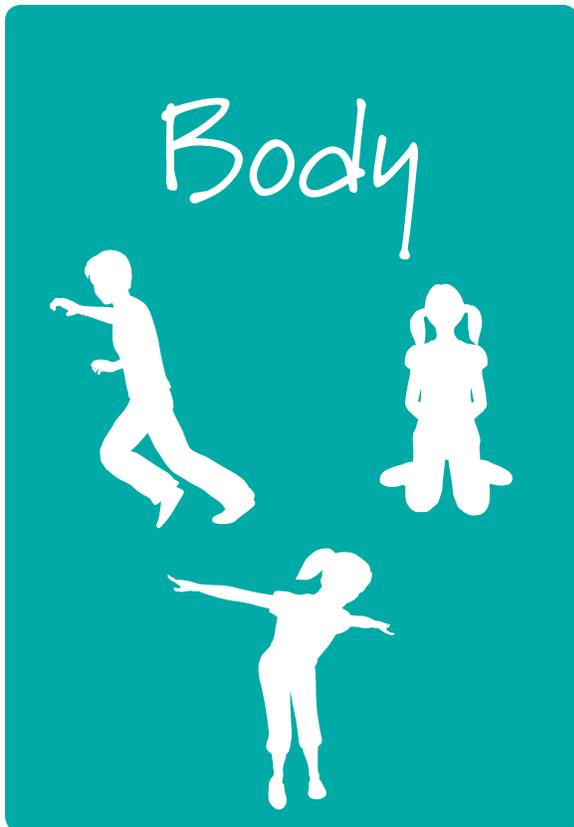
Name one thing you really like about your body.



Why might it be important to know about the changes in your body when you are sick?



When you think about the future, what kind of information about the condition would you like to have?



BODY



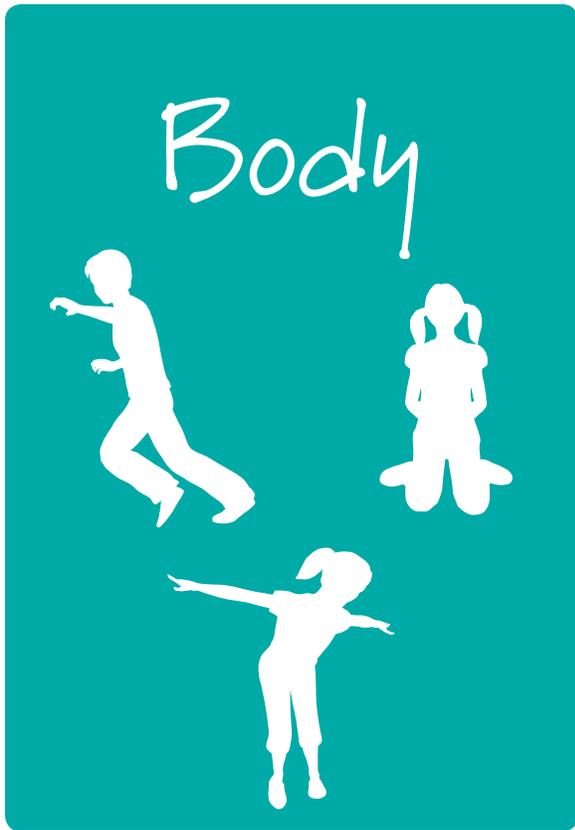
When you are in pain, what are the things your family can do to help you feel better?



What are some words to describe your body when you are feeling pain? How about when you are free of pain?



How well do you feel your family is able to deal with physical pain?



BODY



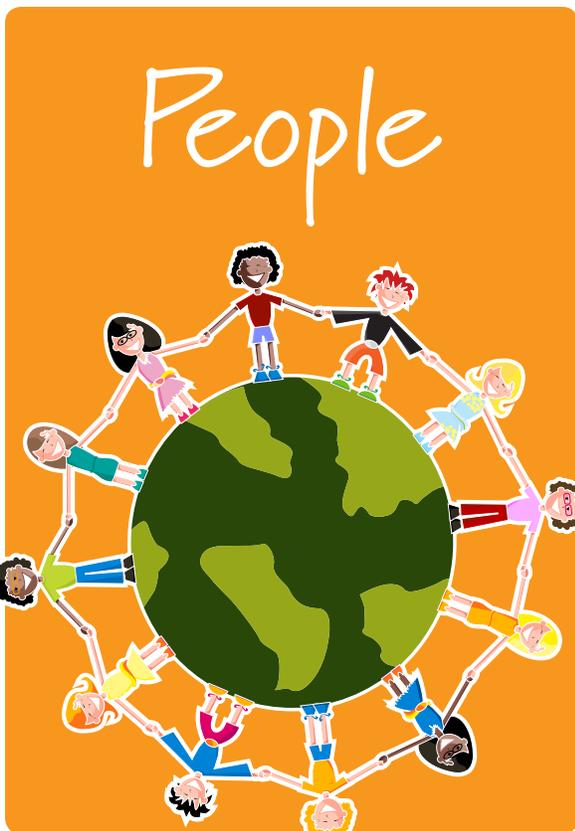
If you could have a magic wand that would fix one hurt in somebody's body, what would you fix?



Of all the symptoms of the condition, which one has surprised you the most?



When you think of the condition in your body or in your family member's body, which of the changes are hardest to cope with?



PEOPLE



If you could choose a present for each member of your family, what would you choose?



How can families share the experience of an illness?



How do you think a family can become stronger from an illness experience?

People



PEOPLE



If you could plan a party, who would you invite and what kind of a party would it be?



Describe a time when you would want to have people around you. How about a time when you would rather be alone.



Describe someone who has been a part of your life for a very long time and who really understands you.

People



PEOPLE



In times of celebration, who do you like to have around you?



How do you like to spend time with your friends? How has this changed because of the condition?



How might a close friend describe you? What qualities are you most proud of?

People



PEOPLE



Imagine that you could enter a time machine and visit a time from your past. What part of your life would you go back to and why?



Everyone makes mistakes. If you had a BIG eraser and could go back in time and erase something you said or did, what would you erase?



How do you describe forgiveness? Why is practicing forgiveness important?

People



PEOPLE



A writer wishes to write a story about your family. What might the title of this story be?



Sometimes people find that a challenge can help them to grow wise and appreciate life. Share something you have learned through this experience?



If you could give advice to another family, what would it be?

Feelings



FEELINGS



What has been the best day you can remember?



What has been most important to you in the last few weeks?



How have your priorities changed since learning of the condition in your family?

Feelings



FEELINGS



People have all different kinds of feelings. If you had the power to get rid of some of your feelings, which ones would you choose?



Sometimes we hide our feelings. Why do you think a person might do this?



What is the most challenging or difficult emotion to cope with? How often do you feel this emotion?

Feelings



FEELINGS



Show on your face what it looks like when you are happy, sad, worried and mad. See if we can guess which one you are showing.



Sometimes our feelings get all mixed up inside. Tell us about a time you felt all mixed up. What helped you?



Intense feelings are a part of an illness experience. What things can you do to express these feelings?

Feelings



FEELINGS



What kinds of things help you to feel safe, comforted, and cared for?



Some people like to be comforted in a certain way. When you feel scared or worried, what helps you?



Describe a time when you felt that someone really listened to you. How did this make you feel?

Feelings



FEELINGS



If you had a magic wand and could take a feeling away from your family, what would it be?

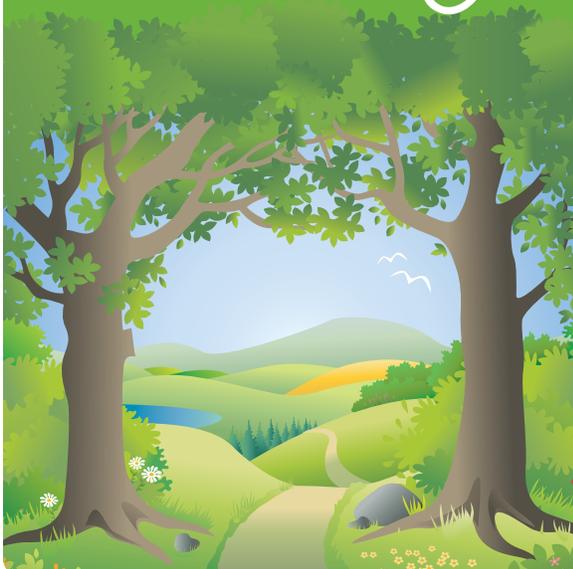


When you think about the condition, what words come to mind?



What emotions appear in your family most often? How do you cope with these?

Meaning



MEANING



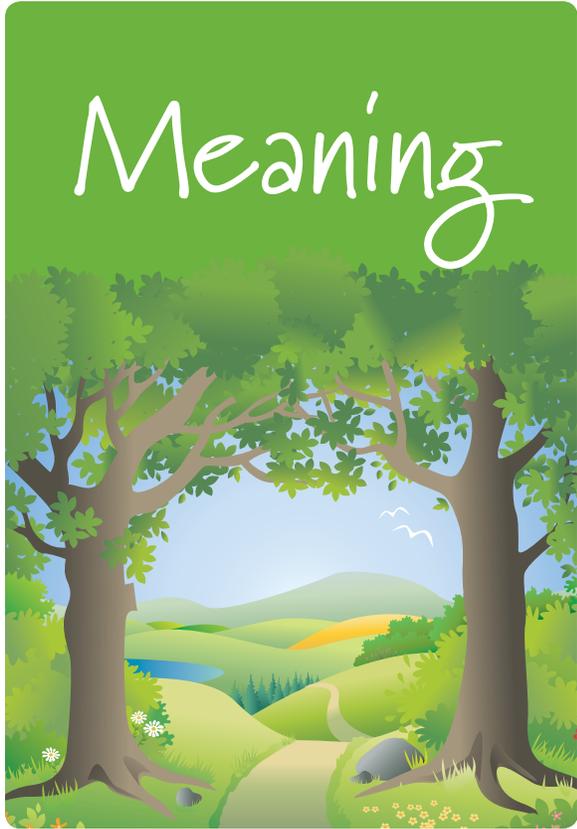
If you were blowing out your birthday candles, what would you wish for today?



When you look towards your future, what are your hopes?



How do you describe hope? Why is it important to you and your family?



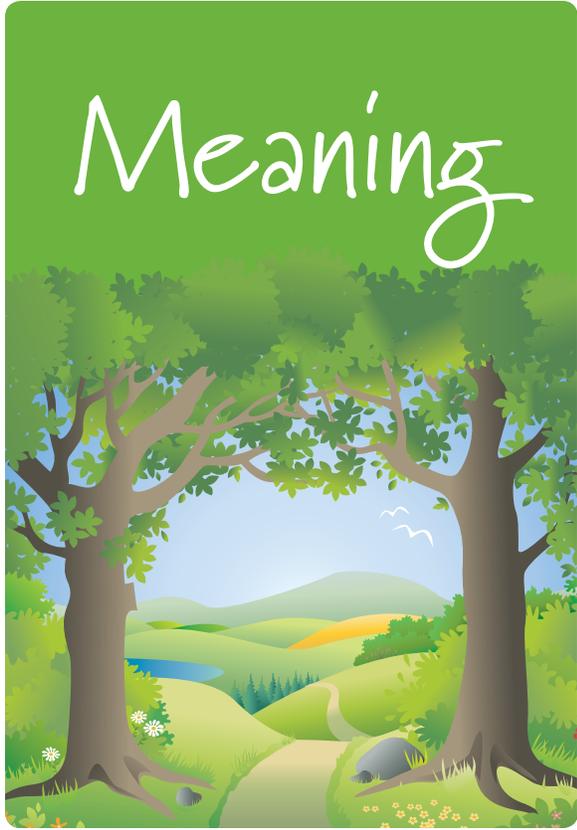
Meaning

MEANING

 Tell us about something that helps you feel strong.

 How is a religious faith or spiritual belief system important to you and your family?

 Some people believe that there is a higher power. What kinds of things do you believe in?



Meaning

MEANING

 How do you pray?

 What do you do to take care of your inner self?

 Do you find prayer or meditation helpful? How are you supported in your beliefs?

Meaning



MEANING



If your family could look into a crystal ball and see the future, who do you think would want to look?



Is there a question you have wondered about for a long time? Feel welcome to ask your question or write it down on a blank card.



Do you believe that all questions have answers?

Meaning



MEANING



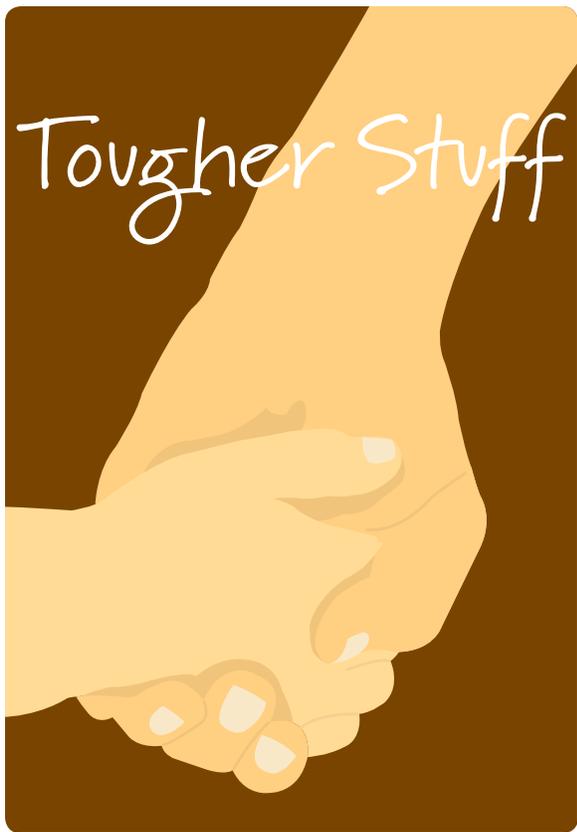
If your family were to do something good in the world that would always be remembered, what might that be?



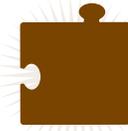
If you could wave your magic wand and wake up tomorrow and the world could be different, what would change?



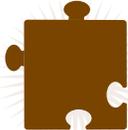
Have you ever had an unexplainable experience that has helped you cope?



TOUGHER STUFF



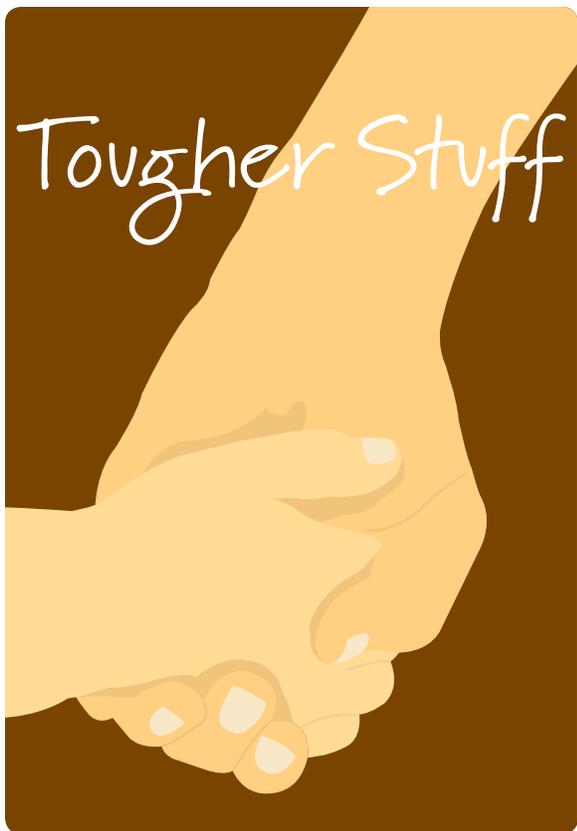
Can you name some people who have died?



When you think of people you know who have died, what do you remember about the experience?



Share your thoughts on what happens to a person after they have died.



TOUGHER STUFF



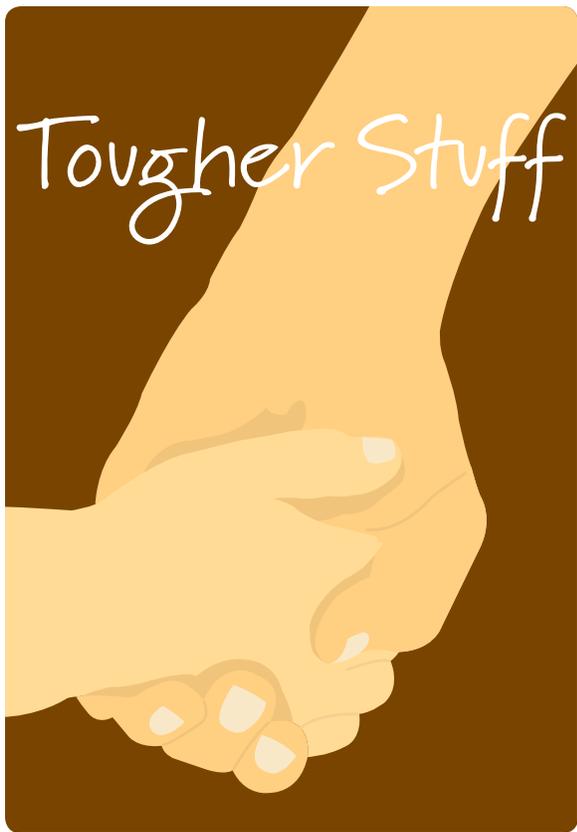
Describe your biggest worry or your worst fear.



Describe a time when you worried about something, but everything turned out just fine.



What kinds of things do you think people who are sick worry about?



TOUGHER STUFF



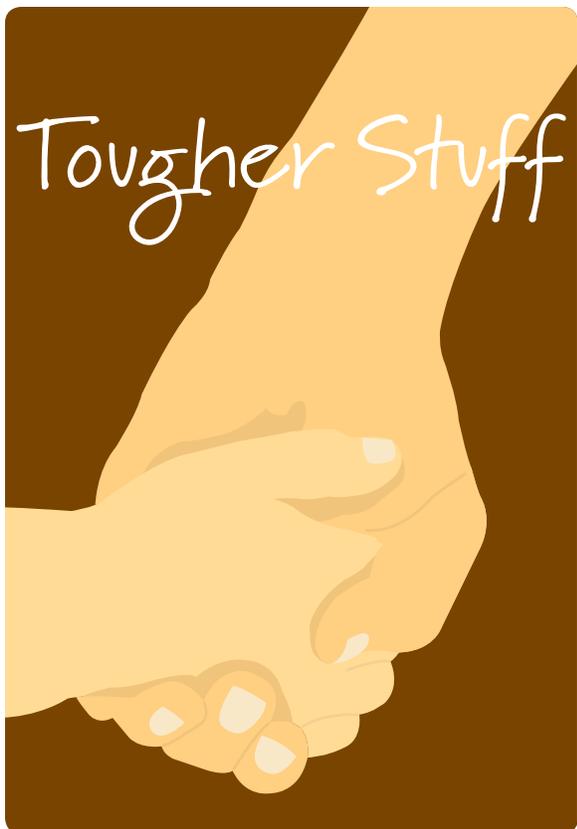
Describe a time when you had a hard decision. What helped you figure out an answer?



Describe some of the things that you do not want to experience or see your family member experience.



Describe what the word "suffering" means to you.



TOUGHER STUFF



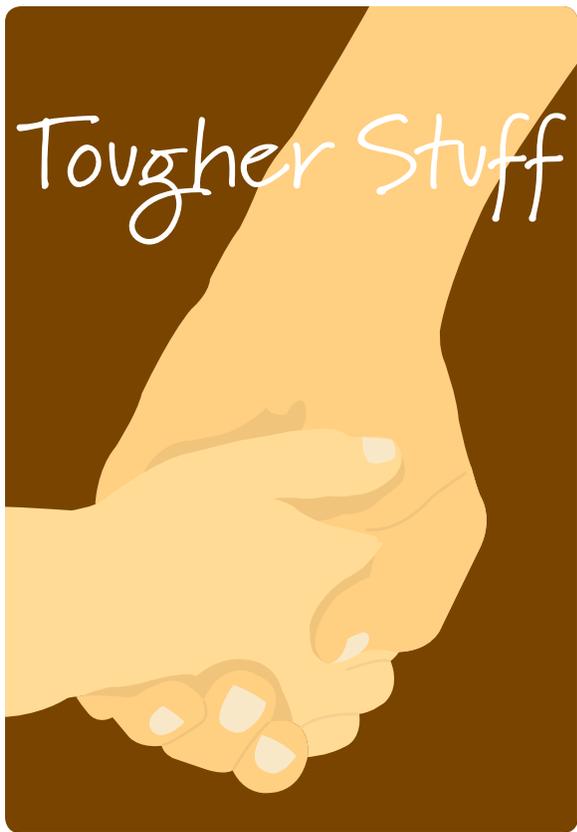
Imagine your family is about to climb a big mountain. What kinds of things can you do to help each other along the way?



As a condition progresses, families need to make decisions about how much medical treatment they want. Who would you like to talk to about the choices you have?



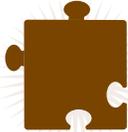
If you could draw a line in the sand to say what medical treatments you are comfortable with, where is that line today? Can you describe what kind of treatments you do not want?



TOUGHER STUFF



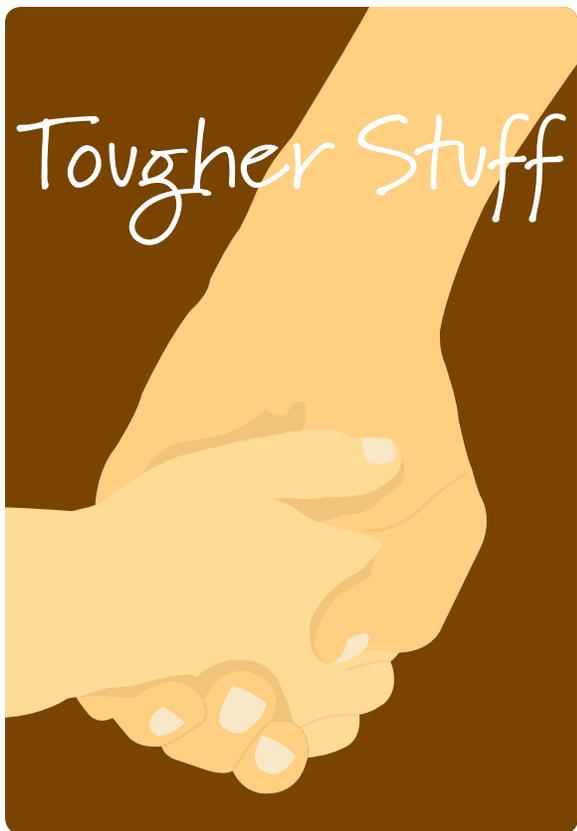
Describe a family ritual or tradition that is meaningful to you.



Share your experience of funerals or memorials.



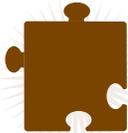
If you could leave behind a legacy or a special way to be remembered, what might it be?



TOUGHER STUFF



Describe the most comforting and special place you can imagine. Include the people, pets, stuffed animals, music and anything else you like.



If a dying person was given the choice of dying at home, in hospital or somewhere else, what do you think they would choose?



When you imagine what things might look like at the end of life, where are you? What and who is helping you?

Wrapping Up



WRAPPING UP



Describe how you feel now that the activity is ending.

Wrapping Up



WRAPPING UP



Name something really great about your family.

Wrapping Up



WRAPPING UP



If you could plan a family holiday, where would you go?

Wrapping Up



WRAPPING UP



Share two ways that you show your family members that you care about them.

Wrapping Up

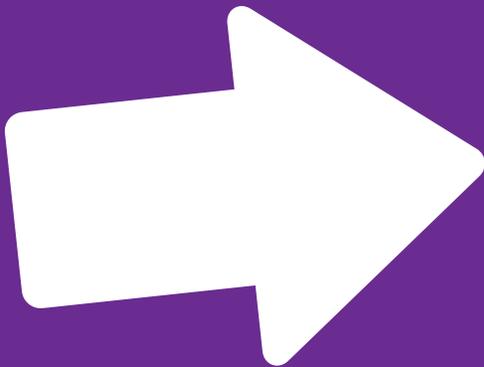


WRAPPING UP



Finish this sentence:
Our family is...

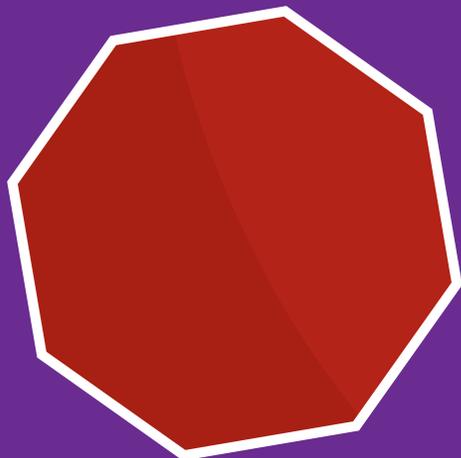
1 Pass



1

Pass

Stop



Stop

This is Important!
Hear My Voice



This is Important!
Hear
My
Voice

Everyone Answers!
Hear Our Voices



Everyone
Answers
Hear
Our
Voices

Ask Me Later...



Ask
Me
Later...

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A white rounded rectangle with a thin purple border. Inside, there are seven horizontal purple lines spaced evenly down the page, serving as a writing area.A white rounded rectangle with a thin purple border. Inside, there are seven horizontal purple lines spaced evenly down the page, serving as a writing area.



