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Survey Title

NINR Survey: Family Support for Children with Serious Illnesses

Survey Introductory Paragraph

The National Institute of Nursing Research (NINR), part of the National Institutes of Health, made this survey to ask for feedback from families and caregivers of children with serious illnesses. Dealing with an illness can be hard for the entire family, and palliative care is an important source of support for everyone. NINR developed the *Palliative Care: Conversations Matter*[®] campaign so that more families can learn about and use palliative care. Before creating new materials for families, we would like to hear from you.

This survey does not collect or save any identifying information, so your answers are anonymous. It should take 10 minutes or less to complete. Please skip any question you do not wish to answer.

Thank you in advance for your help. Your feedback is very important to us and will help us make sure more families get the comfort and support they deserve.

If you would like to learn more about NINR or the campaign, please go to <http://www.ninr.nih.gov/conversationsmatter>.

1. Please tell us your relationship to the child with a serious illness.
 - Parent or guardian
 - Sibling
 - Other family member
 - Caregiver (not a relative)

2. How old was the child when you learned he or she had a serious illness?
 - Younger than 1
 - 1-4
 - 5-9
 - 10-14
 - 15-17
 - 18 or older

3. If you have received palliative care, how did you first hear about it?

- From a health care provider
- A friend or family member
- Chaplain or spiritual leader
- Social worker
- Internet search or website
- Support group or online group
- Other: _____
- I have not received palliative care

4. Below are some of the general ways palliative care can help families. Please rate them based on how important they are to your family.

	Very important	Important	Somewhat important	Not very important	Not sure or no opinion
Taking care of my child's symptoms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting support for the rest of my family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Finding care that respects my values and beliefs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting help understanding medical information	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having extra support to go along with regular care and treatments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Finding out about other types of care like art or music therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Receiving care in my home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having a team of providers focused on my child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Improving communication with doctors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

5. Below are some specific ways palliative care can support families. Please tell us how helpful each would have been when you first learned about the serious illness.

	Very helpful	Helpful	Somewhat helpful	Not very helpful	Not sure or no opinion
Someone to listen to my concerns, feelings, and questions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Someone to help with communicating with all our doctors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Someone who could respectfully help our family make decisions together	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Playtime and companionship for my child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Pain and symptom relief for my child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Someone to help my other child(ren) feel supported	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People to help make sure my child was still getting a chance to be a kid	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Someone to help us make sense of all the information	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

6. What are three things you wish you had known right away about caring for a child with a serious illness? An example might be, "knowing what questions to ask the doctors."

1. -----
2. -----
3. -----

7. Check the top three ways you get health information for your family.

- Health care providers
- Family and friends
- Print materials like books and brochures
- Community or hospital bulletin boards
- Internet search or websites
- Chat rooms, message boards, or online support groups
- Social media like Facebook, Twitter, or YouTube
- TV, radio, or newspaper
- Other: _____

8. How do you usually share health information with others?

- I tell them about it (by phone, in person, etc.)
- I text or email information like articles and websites
- Chat rooms, message boards, or online support groups
- I share through social media
- Other: _____
- I do not usually share resources I find

9. Please use the chart below to tell us what materials would help families most.

	Very helpful	Helpful	Somewhat helpful	Not very helpful	Not sure or no opinion
Information kit with palliative care basics	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Stories from other families living with a serious illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Video how-to guides about palliative care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Podcast series with information or stories	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Facebook page or other social media with information and updates	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Printed materials like fact sheets and resource lists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Online or mobile app with quick tips and resources	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Connecting with other families to share experiences	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

10. If there is something not listed above that you think would be helpful, please tell us here.
