

OMB CONTROL NO.: 0925-0683  
EXPIRATION DATE: 10/31/2016

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### **CONSENT FOR PARTICIPATION**

Before you take the questionnaire today, we need to ask you to formally consent to participate. Please carefully read the following statements and check the box below acknowledging that you understand each statement and agree to participate in the questionnaire.

- a) I understand that my participation is voluntary. I can choose not to answer questions and I can withdraw from the questionnaire at any point.
- b) I understand that all information collected in the questionnaire is secure to the extent permitted by law, and will not be disclosed to anyone but the researchers conducting this study, except as otherwise required by law. All findings will be reported in aggregate.
- c) I will not be asked any personally identifying information when responding to the questionnaire. My personal identity will be protected. A transcript of the questionnaire will be stored securely and will only be accessible to the research team. No one will be identified in reports resulting from this questionnaire.

NINR is authorized to conduct the following questionnaire under section 42USC 285q of U.S. Law.

If you have questions about the questionnaire or your participation, please contact the National Institute of Nursing Research by email at [info@nir.nih.gov](mailto:info@nir.nih.gov) or by phone at [301-496-0209](tel:301-496-0209).

**I am at least 18 years old.**

- Yes
- No

By selecting "I Accept," **I acknowledge and accept the consent statement and agree to participate in the questionnaire.**

- Accept
- I Do Not Accept

Please note: After you've selected an answer hit the "next" button to continue to the next question. You will see a thank you page when you have reached the end of the survey. For open ended questions, please do not enter any personally identifying information. To read NINR's privacy policy, [click here](#).

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Are you...?

Male  
 Female

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What is your age?

Under 18 years old  
 18-24 years old  
 25-34 years old  
 35-44 years old  
 45-54 years old  
 55-64 years old  
 65-75 years old  
 75 years or older

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What state do you live in?

Please select ▼

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Are you a parent or guardian of a child under the age of 18?

Yes  
 No

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In the past 3 years, has your child under the age of 18 experienced any of the following serious illnesses?

*(Please select all that apply.)*

- Cancer
- Genetic disorder
- Neurologic disorders
- Lung condition
- Prematurity
- Heart condition
- Other serious illness
- My child has not experienced a serious illness

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How old is your child who currently or within the past 3 years has had a serious illness? (If you have cared for more than one child with a serious illness, please select the one you have cared for most recently.)

- Under 1 year old
- 1-4 years old
- 5-7 years old
- 8-11 years old
- 12-14 years old
- 15-17 years old

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How familiar are you with the term "pediatric palliative care"?

- Not at all familiar
- Not very familiar
- Somewhat familiar
- Very familiar
- Extremely familiar

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In your own words, how would you define pediatric palliative care?

Not sure/Don't know

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How familiar are you with services that address the symptoms, discomfort, and stress associated with your child's serious illness as well as give support to you and your family?

- Not at all familiar
- Not very familiar
- Somewhat familiar
- Very familiar
- Extremely familiar

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Are you familiar with or have you used any of the following services for pediatric patients and their families?

	Only familiar with this service	Used this service	Not familiar with this service
Counseling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Locating community resources to help your family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Art and music therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Coordinating care and appointments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social work services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Management of your child's pain and other symptoms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Spiritual support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respite care (i.e. giving caregivers a break from their everyday duties)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Where did you first learn about these services, also known as pediatric palliative care?

*(Please select all that apply.)*

- Health fair or community event
- Brochure or flyer
- In-person support group
- A doctor or other health care professional
- Social networking site (Twitter, Facebook, PatientsLikeMe, Google+, etc.)
- Radio
- TV or movie
- Online chat room/board/support group
- Friends or family
- Non-profit, religious or community organization
- Outdoor billboard or outdoor poster
- Online video
- Hospital, clinic, doctor's office, or other medical organization
- Internet search or website
- Email message
- Newspaper, magazine, newsletter or book
- Other (Please specify)
- Not sure/Don't know

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What resources do you currently use to stay informed about pediatric palliative care?

*(Please select up to 5 resources)*

- A doctor or other health care professional
- Email message
- Internet search or website
- In-person support group
- Friends or family
- Outdoor billboard or outdoor poster
- Non-profit, religious or community organization
- Radio
- Health fair or community event
- TV or movie
- Newspaper, magazine, newsletter or book
- Brochure or flyer
- Hospital, clinic, doctor's office, or other medical organization
- Social networking site (Twitter, Facebook, PatientsLikeMe, Google+, etc.)
- Online video
- Online chat room/board/support group
- Other (Please specify)
- Not sure/Don't know

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Please select how strongly you agree or disagree with each of the following statements.

*(Please select one response for each statement.)*

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	Not sure/Don't know
Palliative care means my health care provider has given up and there is no hope for my child.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is no difference between palliative care and end-of-life care for children.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pediatric palliative care can be delivered along with life-prolonging care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Palliative care can be received at any time, whether the illness is terminal or not.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Palliative care is for old and dying patients.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I can only accept pediatric palliative care if the decision is to stop medical treatment for my child.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am hesitant to discuss pediatric palliative care with my health care provider.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Palliative care is the same as hospice care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Palliative care can enhance my child's quality of life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Please select how strongly you agree or disagree with each of the following statements.

*(Please select one response for each statement.)*

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	Not sure/Don't know
I have access to resources and tools to have a conversation about pediatric palliative care with my health care provider.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My health care provider has discussed pediatric palliative care options with me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel equipped with the necessary information to seek out pediatric palliative care for my child if I choose to.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Have you recently heard, seen, or read messages about pediatric palliative care in advertising, publicity, the media, online, or other places?

- Yes
- No
- Not sure/Don't know

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Where did you see these messages?

*(Please select all that apply.)*

- A doctor or other health care professional
- Online video
- TV or movie
- Outdoor billboard or outdoor poster
- Internet search or website
- Non-profit, religious or community organization
- Newspaper, magazine, newsletter or book
- Friends or family
- Health fair or community event
- Hospital, clinic, doctor's office, or other medical organization
- Social networking site (Twitter, Facebook, PatientsLikeMe, Google+, etc.)
- Brochure or flyer
- Online chat room/board/support group
- In-person support group
- Radio
- Email message
- Other (Please specify)
- Not sure/Don't know

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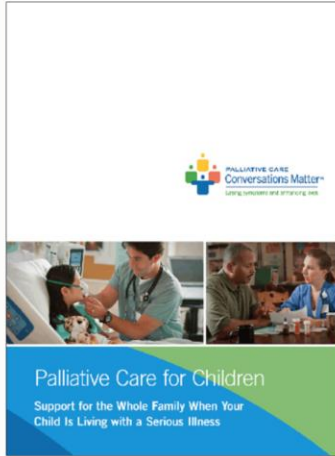
How familiar are you with a campaign called *Palliative Care: Conversations Matter*®?

- Not at all familiar
- Not very familiar
- Somewhat familiar
- Very familiar
- Extremely familiar

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Before today, had you seen either of the following materials, or ones similar to these?



- Yes
- No
- Not sure/Don't know

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Where did you see these materials/learn about the *Palliative Care: Conversations Matter*® campaign?

*(Please select all that apply.)*

- Online chat room/board/support group
- A doctor or other health care professional
- Radio
- Hospital, clinic, doctor's office, or other medical organization
- Non-profit, religious or community organization
- Health fair or community event
- Internet search or website
- Friends or family
- Social networking site (Twitter, Facebook, PatientsLikeMe, Google+, etc.)
- TV or movie
- Email message
- In-person support group
- Newspaper, magazine, newsletter or book
- Brochure or flyer
- Online video
- Outdoor billboard or outdoor poster
- Other (Please specify)
- Not sure/Don't know

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Below are a series of statements about pediatric palliative care. Please select whether you have seen or heard each of the following statements before:

	Yes, have seen/heard this statement	No, have not seen/heard this statement	Not sure/Don't know
<b>Pediatric palliative care...</b>			
Helps your child live a more comfortable life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Can be provided in a hospital, during clinic visits, or at home.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provides comfort and support to your child and family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Focuses on the needs of your child and family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gives you and your family an added layer of support.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Can begin at any time.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Can be given at the same time as other treatments.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provides emotional and social support that respects your family's cultural values.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Surrounds your family with a team of experts who work together to support all of you.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Eases your child's pain and other symptoms of illness.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Below are some benefits of palliative care for pediatric patients and their families. How beneficial are each of these to you personally?

	Not at all beneficial	Not too beneficial	Neutral	Somewhat beneficial	Very beneficial
Helps your child live a more comfortable life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Can be provided in a hospital, during clinic visits, or at home.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provides comfort and support to your child and family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Focuses on the needs of your child and family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gives you and your family an added layer of support.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Can begin at any time.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Can be given at the same time as other treatments.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provides emotional and social support that respects your family's cultural values.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Surrounds your family with a team of experts who work together to support all of you.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Eases your child's pain and other symptoms of illness.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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How likely are you to do each of the following:

	Not at all likely	Not very likely	Somewhat likely	Very likely	Extremely likely
Talk to your loved ones, including your child, about how palliative care can support your family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Visit the Palliative Care Provider Directory of Hospitals to see whether a hospital in your area offers a palliative care program.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Visit <a href="http://www.ninr.nih.gov/conversationsmatter">www.ninr.nih.gov/conversationsmatter</a> for information and resources on palliative care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Talk to your child's health care provider about palliative care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recommend the <i>Palliative Care: Conversations Matter</i> ® campaign materials to other parents and families.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Thank you! Only a few more questions to ask you.

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Are you Hispanic or Latino?

Yes, I am Hispanic or Latino  
 No, I am not Hispanic or Latino  
 Prefer not to answer

To be sure we have a representative sample, what is your race?

*(Please select all that apply.)*

American Indian or Alaskan Native  
 Asian  
 Black or African American  
 Hawaii Native or Other Pacific Islander  
 White  
 Other  
 Prefer not to answer

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What is the highest grade of school you have completed?

Less than high school  
 High school (grades 9-12, no degree)  
 High school graduate (or equivalent)  
 Some college (1-4 years, no degree)  
 Associate's degree (including occupational or academic degrees)  
 Bachelor's degree  
 Master's degree  
 Professional school degree  
 Doctorate degree

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Which of the following best describes the area you live in?

Urban  
 Suburban  
 Rural

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**NIH** National Institute of Nursing Research 100%

Thinking of everyone in your household who receives income, what is the total yearly income for your household before taxes, including salaries, Social Security, pension, interest, and investment earnings?

- Under \$10,000
- \$10,000-\$19,999
- \$20,000-\$29,999
- \$30,000-\$39,999
- \$40,000-\$49,999
- \$50,000-\$74,999
- \$75,000-\$99,999
- \$100,000-\$150,000
- Over \$150,000
- Prefer not to answer

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**NIH** National Institute of Nursing Research 100%

**Thank you so much for completing this survey. Your feedback is very important to us.**

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