Parenting a Child with Life-limiting Illness

A unique film for parents and professionals

Caring, Coping, Surviving

to lessen the feelings of isolation and provide genuine hope

Toolkit for Screening with a Professional Audience

NTSAD

Hosting a Screening Planning Guide

Thank you for your interest in hosting a screening of the NTSAD film, "Parenting a Child with Life-limiting Illness" for friends and family.

This tool-kit includes materials and guidance to assist you with hosting a successful screening. Remember, the NTSAD staff is available should you have any questions. We greatly appreciate your support and efforts to bring this important film to a broader professional audience because healthcare providers with deep insights into the family perspective will provide more compassionate care for the entire family.

We look forward to hearing from you.

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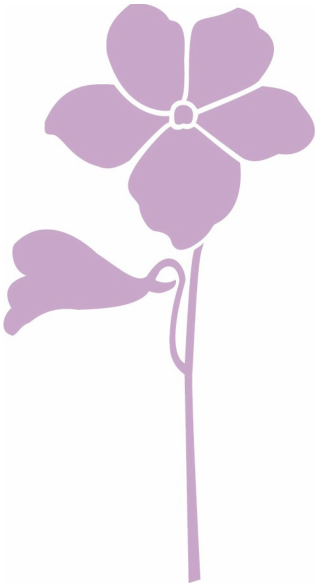

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Logistics

NTSAD Support:

The staff of NTSAD is available to help you through the process of hosting a professional screening. Please contact us to help get started.

Kim Kubilus, Director of Family Services
617-277-4463
Kim@ntsad.org

Time Requirement for the screening: Minimum 1 hour; Optimal 90 minutes.

The film itself is 35:00. We recommend allowing 10 minutes to introduce it (see page 5) and then 15 minutes for follow-up. If you have more than an hour for the entire session, all the better.

Space: Ideally, the film is screened in a large comfortable auditorium with excellent sound and large screen but successful screenings can also be a small group of people huddled around a laptop with a brown bag lunch.

To RSVP or Not RSVP: Asking people to RSVP in advance can be helpful both for planning purposes and for gathering contact information of attendees for follow up after the screening. On the other hand, it does add to the planning time commitment and not all professional development settings require RSVPs.

Collecting Feedback: If evaluations are appropriate in your professional development setting, we greatly appreciate your taking the time to collect the feedback. Options include a paper evaluation handout following the screening, flyer with online evaluation ‘url’ and/or email (if collected) following the screening. NTSAD will provide evaluation materials (paper and online) and will work with you to customize to meet your needs.

Planning Timeline:

* Reserve space for screening; lead time varies with location
* Begin promoting 6 to 8 weeks in advance
* If collecting RSVPs and email addresses, send reminder email two to three days prior to the screening.
* If collecting emails of attendees, send follow up email with survey link within two to three days after screening.

Inviting Colleagues

Promote via flyer and poster. NTSAD will customize a professional screening flyer with the specifics of your event. Post in multiple places.

Promote via e-poster. NTSAD will customize a professional screening e-flyer to post on:
- Hospital / Facility’s Social Media (Facebook, Twitter etc)
- Your personal Facebook page, if appropriate and comfortable to doing so
- Professional Listserves
- Hospital / Facility’s newsletters

Send an e-mail to colleagues:

Sample language –

I very much hope you will join me for a free screening of the 35-minute film “Parenting a Child with Life-Limiting Illness: Coping, Caring and Surviving” on DATE, TIME, at LOCALE. This amazing film is for pediatricians and palliative and hospice providers who seek to deepen their understanding of the family perspective. Topics candidly discussed include:

Coping with the Diagnosis
Finding Support
Caring for Siblings
Working
Tending the Marriage
Involving Family and Friends
Finding a Philosophy of Care
Understanding Palliative and Hospice Care
Making Decisions about Feeding Tubes
Transitioning to the End of Life.

A short trailer is available at http://www.youtube.com/user/ntsad.

For professionals, it provides a unique opportunity to hear parents speak frankly about intimate issues and to deepen understanding of thoughts, fears, needs and realities of parents caring for children with a lifespan limiting diagnosis. A flyer for the event is attached with this email. Please share with your friends and colleagues.

Please contact me with any questions. Hope to see you there!

Warm regards,

Inviting a “Professional” Parent

The participation of a Professional Parent can enhance the learning experience for providers. The ideal Professional Parent is not in an immediate crisis and has constructive perspective without unresolved complicated issues and feelings. If possible, discuss their proposed talk before the screening and review any talking points or themes that are especially important to address.

Contact Kim Kubilus, Family Services Director, at kim@ntsad.org for help finding a “professional parent” to attend your screening.

Preparing for the Screening

The film will be emotional for some in the audience so be sure to have tissues available.

There are two versions of the film:

The family version is slightly longer and includes a section on managing secretions and seizures.

The professional version runs 35:00. We recommend this version for a professional audience.

Allow time to check the Audio-Visual equipment (AV) at least 15 minutes before screening to allow time for troubleshooting.

Introducing the Film and Preparing the Audience

Describe the inception and purpose of the film:

The film was initially conceived by National Tay-Sachs & Allied Diseases to be a support and resource to affected families, but it has also been found to be a powerful teaching tool for professionals. Practitioners may feel inadequately trained in palliative and end-of-life care and uncertain how best to support these families. However, caring for the child with a life-limiting condition necessitates looking beyond the disease and understanding the context and needs of the whole family. Hospital settings and doctor visits do not afford a full view of parents' reality at home or their spectrum of thinking. The film helps with understanding this point of view.

Speaking from the intimacy of their homes, the parents interviewed talk frankly and courageously about issues that extend far beyond the specifics of their child's diagnosis. As such, this film gives providers a privileged glimpse into the personal thoughts, fears, challenges and strategies that families carry and employ while parenting children they know will have a short life. We hope that the film and follow-up discussion will prompt reflection about how to help parents facing similar struggles feel heard, seen, and understood.

Encourage the audience to watch for things such as:

> How what you learn from listening to these families might change how you guide families in your care;
>
> How you deliver the news of a difficult diagnosis;
>
> How you forecast for families some of the challenges and solutions other families have faced (impact on sibling, spouse, work); and
>
> How you can encourage families to articulate and evolve their own philosophy of care.
>
> These are also questions you will be asking in the follow-up discussion.

Share what others have said about the film:

In prepping your audience for the screening, you may find it helpful to share with them what other professional providers have learned from it. Here is a sampling of findings from screenings at a major city hospital with audiences that included medical residents, social workers, chaplains and pediatric intensive care unit doctors and nurses.

Introducing the Film and Preparing the Audience (cont'd)

Everyone who viewed the film noted that it provided a perspective that they rarely encounter. They had a renewed awareness that they meet and get to know patients and families when they are at their most stressed, most-sleep deprived and anxious.

One intensive care unit doctor noted that the families' stories opened his eyes as to how much medical care parents provide for their children at home, so that he developed an appreciation of the medical expertise parents possess.

A nurse commented that given parents' ability to manage a significant amount of medical complexity at home, it became clear to her that parents bring their children to the hospital only when it is absolutely necessary and that they really would prefer to be at home.

One resident credited the film with helping him understand that men and women often cope very differently when they are caring for a child with a life-limiting illness.

Providers articulated that the film prompted them to reflect upon how they might change their practice of medicine and how they interact with patients and families. For example, one said he would include parents more in hands on care and decision-making in the hospital setting. Another said she would ask more questions about the child's home life and baseline status. This prompted a discussion of the need to keep focus on questions of a child's overall quality of life rather than discrete decisions about medical treatments. Another said the film renewed her commitment to asking parents about their needs and what she could do to help them better manage in the hospital setting.

And here is a quote from a Pediatric ICU doctor, which illustrates how unique it is for hospital-based staff to experience the richness of patients lives that is portrayed in this film.

"I do think getting a glimpse into what life is like for these children and their families when they are outside the hospital trying to lead their lives and normalize their environment was powerful. I have a heightened appreciation for how incredibly difficult the road can be for families and how small changes to my practice can have a huge impact on a family -- the way I talk to families, the way I listen to them, the way I think about the discharge plan I send them home with etc. The film took me out of my environment (the PICU) and helped me sense what having a sick child at home is like -- emotionally and physically. While I've always felt I do a pretty good job at seeing the whole person or the whole family rather than the patient or disease, this film really sensitized me to the importance of always keeping in mind that we are mere visitors into a family's life and that we see only a small glimpse of what their lives are like and who they are."

Following Up: Questions for Discussion

When the film ends, give the audience a few minutes to collect themselves and reflect on what they've just watched.

You might then begin the follow-up with such open-ended questions as:

What surprised you, what moved you, what did you hear that will change your practice?

To prompt more focused conversation, the film's Guide includes also includes the following questions for discussion with a professional audience. (These questions were developed by the Pediatric Palliative Care team at Massachusetts General Hospital for Children.)

QUESTIONS FOR DISCUSSION

1. What did you learn from this viewing about the impact for a family of getting a new diagnosis of a lifespan limiting condition for their child? How might what you have heard here change how you deliver such news, and how you advise and support the family?

Some discussion points:

- Understanding that any diagnosis is a loss, that parents will be in mourning, grieving the loss of a "healthy child", a perfectly envisioned future for example, (the prom, the wedding…).

- Understanding that what is needed is "whole family care," not simply medical care of the affected child. For instance, be prepared to advise regarding how to support siblings for example (clarify their questions so you do not answer more than what they are asking, make sure they understand that they did not cause this, will not catch this).

- Identifying sources of support for the family, including other parents as resources, and reframing hospice/palliative care as life affirming, not "giving up" or only for end-of-life care.

- Choices about working outside the home will have to be made on both a practical and emotional basis. Again, no right or wrong answer. Each person and family is different.

- Keep the marriage/relationship a priority. Parents need to understand that their partners grieve in their own way; discuss the importance of sharing the responsibility of any decisions.

Following Up:
Questions for Discussion (cont’d)

- Friends and family are important players, and may surprise parents in their ability, or lack thereof, to provide support. Parents may learn to “give them a pass.” They won’t necessarily understand what will be most helpful to the family unless parents are able to educate them and ask clearly.

- Although parents may initially feel overwhelmed with what they do not know, they may find that they will become the experts, even more so than the clinicians. Be prepared for that.

- Although the child’s life will be vastly different from that imagined, the goal of a full life for such a child is still attainable.

- For families you are meeting at a time remote from diagnosis, asking about what that time and experience was like for them will deepen your understanding of how to give them the best care.

2. A philosophy of care is a framework of care goals and values to help you make the best choices for your child and family. Philosophies occur along a spectrum from less intervention to a more technical approach. How can you help families explore and come to an understanding of what their philosophy of care might be?

Some discussion points:

- You will need first to acknowledge to yourself your own emotions, values, and framework and how they might be different from those of the family you are advising. As a guide and facilitator, the key is to be non-judgmental and non-directive.

- Ask families what they use for touchstones for decision-making—e.g., their child’s comfort, the wellbeing of the family, the choices that will let them feel they were the parents they wanted to be, that will leave them with the fewest regrets, etc.

- Forecast that a family’s goals and Philosophy of Care may change over time. Exploring this in the hypothetical “what if we knew for certain that no matter what choices we made, her disease would run its course in x months, what would make the most sense to focus on?”

- Affirm that parents can trust their own ability to know what their child is telling them.

- Introducing palliative care/hospice as supportive services that may fit well into a family’s philosophy of care without implying that they are giving up on their child.

Following Up: Questions for Discussion (cont’d)

3. Has viewing this video changed how you would discuss the pros and cons of BiPAP trach or other similar interventions?

Some discussion points:

- As above, you will need first to acknowledge to yourself, your own emotions, values, and framework and how they might be different from those of the family you are advising. As a guide and facilitator, the key is to be non-judgmental and non-directive.

- Understand how the goal of feeding might be different in this setting and help the family explore their goals. For instance, do goals include extending life, feeding for comfort, promoting healing? Forecast that those goals might change over time.

- Several families in the video decided against technologic interventions offered with the intent of extending the duration of a child’s life. Often we say “she needs a G-tube.” What language can we use to offer family choices without bias or judgment?

- The effort to feed a child, to administer needed medications, and to cope with the stress of respiratory compromise stemming from oral intake as a child loses swallowing ability, can affect the quality of life of caregivers/family, as well as the time caregivers may have to tend to self-care, the partner, the other children. A GT may relieve some of those stresses.

- Providing feeding and hydration through artificial means, like an NG or GT, will likely extend life, but may not contribute to the quality of that life, and may simply prolong a natural process of dying.

- When there is no good option, there is no wrong answer.

4. Has viewing this video changed your own understanding of hospice and palliative care? Will you be able to use the experiences of these families to introduce palliative care earlier? Or to help describe for your own patients and families what the end of life might look like for their child?

Some discussion points:

- Palliative care can be offered at the time of diagnosis and should not be reserved for end-of-life care only.

Following Up:
Questions for Discussion (cont'd)

☐ Families may not be able to voice their unspoken questions about end of life and may need us to offer information, forecast choices (such as venue of care at home or facility, resuscitation status), give information about signs that may indicate the end is near.

☐ Exploring a family's biggest hopes and fears around the end of life for their child will allow them and their caregivers the chance to address them.

☐ Can a child be "perfectly comfortable to the end"?

5. Is there anything that you found yourself wishing you could have asked these families that was not addressed?

NOTES: