A place of respite
for kids and families
Crescent
Cove

Actions for Impact

Summary of Crescent Cove Symposium 2015 Insights

October 16-17, 2015
LifeSource Conference Center

Over 50 community leaders met to explore actions to enhance the availability of resources and relationships for respite and hospice care needed by kids and their families in the Upper Midwest. This document summarizes the many ideas, issues and initiatives they recommended for the leaders of Crescent Cove to consider as it develops its strategic plans for 2016-2020.

The summary captures information in four spheres of interest:

1. Needs of kids and their families
2. Policy making challenges and actions
3. Developments in clinical dimensions of palliative care
4. Insights into spiritual and emotional support

A "999 Action Plan" was also developed from their insights for Symposium follow-up and follow-through

Readers are encouraged to reflect on these suggestions and offer refinements or edits that can help strengthen the work of Crescent Cove over the coming year.

The Symposium Moderator offered these ten words to provoke the thinking and planning of the Symposium participants:
Gaps. Grief. Glee. Guilt. Gold. Government. Gateways. Generations. Greatness. Guidance.

Panel Insights into needs of kids and their families

Participants offer the following ideas as challenges and actions:
Challenges:

1. Fragmented "system" of services for kids and their families facing life-limiting conditions
2. Too much focus on clinical/medical interventions and not enough focus on quality of life. Death too often seen as a failure rather than a natural part of life (event though it seems unfair and difficult)
3. How should provider's best introduce hospice and palliative care as an option for parents? Can we provide a guide and script of options?

4. Need more provider education and sensitivity about palliative care for kids
5. Lack of money for providers/hospitals/home care agencies for services and for respite/hospice home
6. Some families remote from Metro providers and support. Need virtual links and support for continuity of services access
7. Families need mentoring and guidance in how to balance support for the rest of the family
8. Providers need help to better appreciate differences between “patient centered care” and “family centered care”
9. Religions and ethnic differences in understanding or supporting end of life services
10. Medical community does not fully understand the array of services, support and therapies that are available in region and how best to access them
11. Lack of information and support guidance for funeral arrangements
12. Lack educational component in schools of medicine and nursing about modern palliative care
13. Lack of reimbursement to families and providers for their costs to access needed support, clinical and therapeutic services
14. Lack of public and societal conversation about pediatric palliative care and hospice and respite settings
15. Insensitive care providers who ignore the families as they face difficult support needs
16. Lack easy access to the array of choices in support in non-clinical arenas of spirituality, music, touch, nutrition etc.
17. Lack space in which parents can meet others and explore issues and options
18. Need time for parents to help engage and support other siblings
19. Nursing and other therapists shortages
20. Not enough palliative care providers
21. Poor reimbursement from public and private payers for palliative care outside the hospital or beyond in-home hospice
22. Medical model is not fast enough or integrated enough to meet needs of families
23. Others?

Actions:

1. Invest in educational programming for care providers about unique needs of families for integrated services access and emotional support
2. Explore more work for “mindfulness” among families and providers
3. Organize Task Force of Payers to design “Insurance Pool Product” that they can/must all contribute to (similar to the workers comp state pool”)
4. Organize parents support and mentoring groups around the state
5. Call for policy makers and foundations to invest more in funding for provider education about palliative care and family integrated services systems
6. Facilitate more story telling and sharing among families and providers and policy makers
7. Arrange for another Symposium like this for more families with those experienced in other cultures and nations
8. Develop annual media and faith communities briefing programs to stimulate maturation of public awareness and understanding

9. Publish series of pamphlets, web based informational references, and virtual webinars for families, parents, grand parents, siblings and providers about the value of and options for Palliative Care for kids with life-limiting conditions
10. Organize sets of workshops like a community college catalogue of such programming as:
    a. Memory Making
    b. Funeral Planning
    c. Sibling/youth grief resources
    d. Others?
11. Develop a bolder communication strategy and materials for the Crescent Cove plans and resources
12. Develop "Parent Mentoring Network" supported by Crescent Cove staff and volunteers
13. Conduct more research into the data and stories of need for this form of support and services
14. Develop directory of family support groups, grief therapy, marriage therapy, marital support and bereavement
15. Crescent Cove needs to invest in an expanded role for its services, respite services and information as a "concierge" for families
16. Publish awards and recognition profiles of superior providers that are acknowledged as very supportive of families and kids
17. Organize clergy roundtables among all faith communities
18. Publish a series of inspirational family stories for targeted audiences like parents, grand parents, siblings and care providers
19. Others?

Panel Insights into policy making challenges and actions

Participants offer the following ideas as challenges and actions:

Challenges:

1. There is a lack of understanding and appreciation among policy makers of the value and need for respite and hospice care for children and their families. Not enough people see the palliative care can be as valuable as intensive curative care
2. The policy map for this complex array of support and services requires a mapping of issues that seeks to make it clearer and as simple as possible for policy makers and the media
3. The palliative care arena for kids has lacked a visible and articulate champion in the legislature and department for health
4. The financing requires engagement of private players like HealthPartners and Blue Cross as well as Medicaid and Medicare to make a meaningful dent in the problem of funding gaps
5. The Crescent Cove message needs to be shared with essential few words and powerful facts and human interest stories
6. Take our story to the legislative leaders and staff, along with Department of Health leaders in a bolder call for funding support
7. Lack of data and epidemiology research of scope and nature of need in Minnesota

Actions:

1. Publish a collection of legislation and policies from other states for modern palliative care and system integration systems
2. Cultivate champions with Nick Zerwas and Matt Dean (see 999 Action Plan below)
3. Define small team of faculty researchers to assemble data base ion the value of modern palliative care and support services. Seek funding for this from UnitedHealth Care group's Optum and other foundations
4. Seek communication experts to help us change the dialogue about death and dying so it is a story people want to hear and understand. Needs to be powerful "One Pager"
5. Some observe that "We want to support causes of sunshine and light" …what if these are the same with the palliative care sphere?
6. Keep working to define the real stakeholders and engage them in the conversation and planning
7. Continue to distill lessons from other states and countries that push Minnesota in to the innovator role
8. Others?

Panel Insights into Developments in clinical dimensions of palliative care

Participants offer the following ideas as challenges and actions:

Challenges:

1. Poor reimbursement arrangements among both government and private payers
2. Little information sharing among the children's hospitals. Too many egos and too few resources
3. Fragmented care system with inadequate information for families and providers about the value of and methods for modern palliative services for kids and their families and grief
4. Providers Lack understanding and skill at making bereavement and grief support available for the kids and families
5. Palliative care is time consuming and offer weak reimbursement for provider time
6. Lack of smooth, interoperability of Electronic Health Records among providers and payers and families
7. Tensions and fragile cooperation among specialist in care for these challenging illnesses
8. Crescent Cove is small and young organization but can help be a catalyst among the bigger hospital based providers
9. Many providers lack understanding of how and where Crescent Cove fits in the respite/hospice service continuum
10. Care is too often taking place in expensive hospital settings or in-home. All are needed but must be more coordinated and collaborative for the needs for the kids and their families
11. Confusion and stigma of the failed "Deva House" model in St Paul makes donors cautious
12. Providers do not understand how the quality of care and service standards in Crescent Cove model will be managed
13. There is a fog in which families struggle to secure services and support

14. Providers can benefit from readings from Chris Fendtner in Pediatrics Clinics of America (2007) and papers from Australia
15. Others?

Actions:

1. Explore shared research initiatives on epidemiology, clinical, economic, political and emotion value of more integrated models of palliative services and information clearinghouses
2. Invest in more grief support for staff as well as families
3. Create regional training for all staff of all Minnesota and regional provider and systems
4. Explore funding for interfaces between the Electronic Health Records needed for coordinated kids care among the competing hospitals
5. Develop grief support from time of initial diagnosis
6. Develop system for families to collect and share their data on experiences, treatment, results, lessons
7. Providers need to support Crescent Cove as a neutral and safe space for collaboration that is both kid and family centered and more cost effective This neutral ground can also help assemble and deploy scarce capital funding needed for programming, studies, services, technologies and healing spaces, facilities, gardens Crescent Cove as the sheltered harbor among the storms of evolving services and systems of support.
8. Approach Epic Corporation in Wisconsin for grants to support interoperability of EHRs among the providers in region
9. Convene therapists to strengthen care and support programming for wide array of initiatives raging from memory making, to respite breaks for siblings and parents
10. Explore more cross privileging among health workers and clinicians like they do in Canada and UK
11. Develop programming that values staff engaged in these forms of services (ensure they are not first ones cut when fiscal squeeze occurs)
12. Help support the Pediatric Palliative Care Coalition of MN and the MN Network of Hospice and Palliative Care in its important work
13. Others?

Panel Insights into spiritual and emotional support

Participants offer the following ideas as challenges and actions:

Challenges:

1. Lack appreciation among public, media, policy makers, providers and families about the large value that spirituality and emotional support play, and therefore the value of alternative therapies and providers in the palliative care mix
2. Gaps in the availability of access to emotional and spiritual support among diverse community groups, rural and urban
3. Staff not exposed enough to palliative care: need curricula, need practicums, need mentors, need awards and recognition of those that “get it right”

4. Lack forums for clergy of all faith groups to meet with providers and researchers
5. Lack collaboration among various therapists and clinicians
6. Policy makers are not encouraged to invest in alternative therapies
7. Generational shifts in communication styles and systems (texting, social media that can either frustrate emotional support, or be harnessed for new forms of support)
8. A society that favors the excitement of health and growth compared to the challenges of death and dying and grief
9. Staff burnout that could benefit from emotional support and grief counseling
10. Lack conversations about spirituality and its epidemiological value
11. Lack receptivity to traditional healers and their reliance on alternative views of spirituality
12. Others?

Actions:

1. Need to invest more media stories in schools, universities and general public on value of spirituality to healing and comforting processes
2. Crescent Cove needs to forge new strategic alliances with other organizations and communities to champion expanded studies, stories and sympathy for modern emotional support services and systems
3. Need more conversations and programming in Crescent Cove leadership about spirituality and self-care initiatives
4. Publish a collection of art by children and siblings who are experiencing "The Journey" of palliative care
5. Publish a small book on how many faith communities deal with death and dying and celebrate the end or passing of life
6. Convene more of these type Symposiums
7. Foster "Parents Days" to share stories and expand the base of support for new services and a new facility
8. Develop more grief support groups in selected communities
9. Form a Task Force to explore and publish materials on "Woven Care" that relies on more collaborative "human bridges" among families, providers, therapists and policy makers
10. Develop more staff engagement programming on grief and spirituality resources and techniques
11. Ensure that Crescent Cove home has space and gardens to nurture chapels and mindfulness
12. Others?

999 Action Plan for Symposium follow-up and follow-through

To help ensure that the many good ideas and suggested initiatives actually result in improved support and services for kids and their families needing respite and/or hospice care for their life limiting conditions, the participants were asked for their final short list of actions that should be accomplished within the next 9 days, the next 9 weeks and the next 9 months. Please review and comment on their suggestions to the board of Crescent Cove. (All of the ideas are listed in random order from the forms)

Actions for the Next 9 Days should be:

1. Publish a summary of the Symposium, celebrate the momentum from this event, and discuss how to build broader understanding of and support for the conclusions and recommendations from the event.
2. Connect with Representative Nick Zerwas to set up Legislative Task Force and schedule face to face social with families and legislators
3. Design and use a “Survey Monkey” to poll families achievable, concrete objectives for modern continuum of services from home to hospital to Crescent Cove type respite center
4. Use the ideas from this event to guide Crescent Coves short and long-term plans and investments.
5. Explore how Crescent Cove can strengthen its role as a resource for families, and a care navigator or “systems’ integrator” among providers and payers.
6. Crescent Cove needs to hire a development director
7. Plan another Symposium and be sure to get private payer participation (Blues, Medica, UCare, others)
8. Build an inventory of services that are currently available
9. Prioritize next steps
10. Develop a legislative and lobbying plan with expert help from people attending his symposium (see 9 weeks plan below)
11. Develop clear “***Gap Analysis***” that guides the strategic planning and budgeting for Crescent Cove
12. Find more unity and collaboration among the three children’s hospitals’ medial. Administrative and board leadership for these type services
13. Continue to listen to the families. They will tell us what they need.
14. Develop volunteers to establish an “***Educational Program***s” for health professionals about these palliative, respite and hospice services (for their university education and for post-graduation from professional societies, hospitals and Crescent Cove
15. Continue to support and engage in Minnesota Palliative Care Network
16. Continue to spread the word about need and engage with and nurture relationships with all of the people at this Symposium
17. Assemble small group to conduct annual needs assessment and Gap Analysis on family needs for respite, hospice and referral services that are customized to needs of each kid/family
18. Tell one person everyday about the messages from this Symposium
19. Share learning from the Symposium for the architecture team
20. Others ??

Actions for the Next 9 Weeks should be:

1. Solidify the overall Crescent Cove political and advocacy goals and strategies
2. Develop action plan to achieve these goals that is endorsed by the Minnesota Palliative Care Consortium
3. Schedule and sponsor a "Compassion and Grief Workshop for parents and providers that is focused on using very practical tools and community resources for care coordination
4. Develop guidelines with our Clinical Council about the degree of illness/pain/intervention that Crescent Cove is able to cover in the residence
5. Define legislative agenda that defines 2-3 priorities and backs it up with data and stories from real families to change the policy framework for pediatric palliative care in residential settings similar to UK and Canada
6. Circulate results from this Symposium to the entire Crescent Cove data base of volunteers, donors and supporters
7. Secure group of donors that can help support this type of Symposium as a series, as well as donors do the Crescent Cove role in care navigation and those that like the respite/hospice home venue
8. Develop and post on CC website progress reports/stories about the full range of support for kids and their families, and for care givers that serve them
9. Organize a quarterly "Parents' Day" for parent to share stories and provide mutual support with each other
10. Explore help from local communication experts on how to shift the public and media and provider conversation and words from death and dying to more engaging messaging
11. Encourage Crescent Cove leaders to actively support the Palliative Care Network/Consortium
12. Tale a leadership position in we b based and referral support system for families and care providers for kids palliative care
13. Develop a plan to add new curricula into schools of medicine and nursing in state
14. Arrange meeting with digital communication and referral companies to adopt Crescent Cove as a 24 hour resource for information and services access
15. Others?

Actions for the Next 9 Months should be:

1. Hire a bold development director
2. Try to form Crescent Cove as a joint venture collaborative among the three Children's Hospital organizations
3. Organize another Symposium with private payer participating as well for next Fall 2016
4. Organize a "***learning session***" for Legislative and Department of Health about these topics
5. Others?